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ABSTRACT

The ten chapters of this book address sexuality issues in the lives of school age individuals who are deaf-blind or significantly developmentally delayed. It notes that these individuals usually do not experience sexuality through typical relationships and thus require a different type of instruction. Chapters have the following titles: (1) "Introduction to Sexuality Education for Individuals Who Are Deaf-Blind and Significantly Developmentally Delayed"; (2) "Sex Education: It Is Never Too Early To Start with a Child Who Is Deaf-Blind"; (3) "Developing a Process for Intervention and Instruction"; (4) "Modesty"; (5) "Appropriate Touch and Personal Boundaries"; (6) "Menstruation"; (7) "Masturbation"; (8) "Sexual Health Care"; (9) "Sexual Abuse". The final chapter is an annotated bibliography of resources and readings related to sexuality education. (DB)

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Introduction to Sexuality Education for Individuals Who Are Deaf-Blind and Significantly Developmentally Delayed

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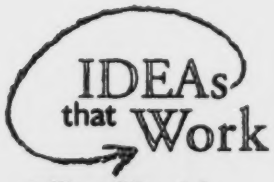
Sha states: *"This painting shows the love I have in my heart for all people."*



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Chapter 1

Introduction to Sexuality Education for Individuals Who Are Deaf-Blind and Significantly Developmentally Delayed

When we first talked about developing these papers for DB-LINK, we had a clear idea about what we wanted to do. As we got into the project, however, that changed. We began to realize all over again just how difficult it is to provide sexuality education to the individual who is deaf-blind. In addition to the normal issues of providing sexuality education to any child, there are unique issues for the child who may not be able to use his vision and hearing well enough (or at all) to access the information. We learned and "relearned" a lot as we worked.

We wanted to write this book to focus on a particular type of child who is deaf-blind, the child with additional significant developmental delays. This type of child has very rudimentary communication skills, is inwardly focused, and is not likely to seek out other people to engage in typical social interactions. This child often has additional physical disabilities and may be considered to be cognitively impaired. Independent travel and basic mobility may be significant obstacles. Most thinking and interactions are tied to very concrete experiences. He or she may be very dependent on others for basic care giving needs. Understanding the abstract "rules" of our society, especially those about the expression of sexuality, may be impossible for this child or young adult.

For that reason, as you read this book, you may find yourself saying, "Where is the sex?" We do not discuss dating, sexual orientation, teaching safe sex, and so forth. Why? Because the type of child or young adult who is the focus of this book does not typically experience sexuality in that way. Most people in this child's world are external forces to be avoided rather than companions who are sought out and engaged. For this individual, the universe is limited to what can be found within the sphere of sight, sound, and touch. This child will probably not seek out typical relationships with others and is more likely to allow only a trusted few to engage him or her in any significant way.

Some of the information we provide in these papers may apply to other types of children and young adults with deaf-blindness. The deaf-blind child who is more social, who has good communication skills, and who does have a basic understanding of "rules," has an entirely different set of needs related to sexuality education. These children will probably understand and seek out others as a source of sexual gratification and affection. They may be interested in having a boyfriend or girlfriend. They may want to date, have intercourse, marry, have children, and so forth. These children and young adults need the kind of sexuality education that their non deaf-blind peers experience (or should experience). Of course, because of their deaf-blindness, that instruction must often be significantly adapted. Professionals and parents who are providing sexuality education for these individuals face some difficult challenges in knowing how to make those modifications in instruction. This publication may be of less use to individuals trying to address the educational concerns of these children and young adults.

When we began our research for this project, we discovered many publications written in the 1970s and early 1980s addressing sexuality education for individuals with deaf-blindness. A lot of that material targeted the higher functioning individual. Jan Neff, among others, contributed many articles on this topic. We have come away from our research with the belief that much of this earlier work should be reprinted and/or updated.

Recently, little has been written about sexuality and the individual with deaf-blindness. The exception is the work done by Maurice Belote of the California Deafblind Project and Tom Miller of Perkins School for the Blind. We are grateful to them for their contributions to this field of knowledge. It is our hope that they continue to write about this topic and share their knowledge with others. We benefitted from their efforts and appreciate the feedback they provided to us.

Our greatest hope for this publication is that it will be helpful to parents. We want to motivate them to provide sexuality education very early in the life of their child. We think that if parents understand that sexuality education begins in teaching the basic body concepts and social rituals we use every day, maybe they won't be so afraid of getting started. We want parents to recognize that inappropriate sexual behavior puts their child at great risk for failure in all areas of his or her life. If they do, perhaps they will avoid allowing bad habits to get started that will later work against their child. We also want to help them acknowledge their child's vulnerability in the world without becoming paralyzed by fear. We believe that openness and communication are key to keeping children safe.

The feedback we received from a number of parents was invaluable. We owe a debt of gratitude to the families in Texas who agreed to read our first drafts: Tim and Cathy Allen, Keith and Leslie Fansler, Sharon and Michael Galvan, Chris and Vivecca Hartman, Glenda and Rod Hellyer, Fareed and Rubina Kahn, Mark and Cindy O'Dell, Celestine and Riley Rand, Diane Shepard, Stephanie and Robert Stultz, and Patricia Williams. We are also grateful to Sally Prouty, parent and director of the Minnesota Deafblind Project, for her support and feedback. Thanks to everyone for telling us how to share information about this sensitive topic with families.

We also appreciate the staff at DB-LINK who found obscure references, directed us to Web sites, clarified our thinking, and most of all gave us a chance to write this book. Without their vision and support, this document would never have happened. Thank you John Reiman, Gail Leslie, Betsy McGinnity, Randy Klumph, and all the others who helped pull this together.

At the root of what we know are the experiences we have had through our work and the work of our colleagues. Thank you to the staff at Texas School for the Blind and Visually Impaired (both past and present) and Texas Deafblind Outreach, especially K.C. Dignan, David Wiley, Garner Vogt, and Nancy LeVack for sharing their knowledge with us. We would like to single out Cyral Miller, Outreach director and our boss, who helped us find time to write, was an exceptional editor, and provided our best support.

It is our hope that this publication is only the first of many new materials about sexuality education for individuals with deaf-blindness. We strongly encourage other professionals and family members to find time to share their knowledge about this topic with others. Like the rest of us, people with deaf-blindness have the right to be sexual beings. It is part of who they are. Like the rest of us, they need information and guidance to be able to express their sexuality in socially appropriate and safe ways. As loving parents and caring professionals, we owe it to these children to provide quality sexuality education right from the start.

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Chapter 2

Sex Education: It Is Never Too Early to Start With a Child Who Is Deaf-Blind

If you are a parent of a young child who has stumbled upon the topic of sexuality education for the first time, you may wonder, "Why should I read this now? My child is still a baby." Even if you are the parent of a somewhat older child, say ten or eleven, you may still be asking yourself, "Is sexuality education something I really need to be thinking about?" If your child is deaf-blind, and especially if he or she has significant developmental delays, we believe sexuality education should be a part of his or her instruction. We also believe that education in the area of sexuality cannot start too soon and that it is never too late to begin. Fundamental to our belief is the fact that although there may be many unknowns in your child's future, you can be certain that your child will always be a male or a female. He or she will have some aspects of sexuality that can be shaped with intervention. This instruction is often key to successful inclusion in society. Sexuality education is something we think you need to learn more about.

What Do We Mean By Sexuality and Sexual Education?

As you will learn, sexuality and sexuality education has a different focus for the child with deaf-blindness and significant developmental delays. Early on, the focus is the development of and self-expression related to gender identity, modesty, and appropriate touching. After the child establishes some of these basic concepts, specific instruction around menstruation, masturbation, personal hygiene, physical health and development, and prevention of sexual abuse must also be included. For certain individuals, instruction may also need to include information about dating, sexual orientation, practicing safe sex, topics covered in more typical sexuality education programs. However, even at that level, the focus is a bit different since concept development is an ongoing issue for the child with deaf-blindness.

In this chapter we want to provide an overview of the issues pertaining

to sexuality education for this population of children. In each of the following chapters we take an in-depth look at a particular aspect of developing sexuality education for this child. We include information on developing sexuality education programs in a school system, teaching appropriate touch and modesty, and addressing menstruation, masturbation, coupling, sexual health, and sexual abuse. The last chapter offers readings and resources that we feel will get parents and professionals started in providing this instruction and supporting children with deaf-blindness and significant developmental delays.

Who Are We Targeting With This Book?

This book is designed for parents, professionals, and other caregivers working with school-aged children who have combined vision and hearing loss or deaf-blindness coupled with significant developmental delays. Some part of this information has application for all deaf-blind children. Even those individuals with great capacities for language and above-average intelligence have some of the same issues in terms of accessing incidental information in their environment. However, our primary focus is on instruction for deaf-blind children who have limited or emerging linguistic skills and who may also have cognitive deficits. We are targeting this group because most commercially available materials do not address the access issues that occur as a result of limited formal language and sensory losses. These products do not take into consideration the need for systematic concept development and instruction in areas that most children learn incidentally.

Because this book is meant to focus on the deaf-blind child with developmental delays, you may not find all of the information you need if the child you are concerned with does not have significant developmental delays. The child with more sophisticated communication skills and who is more socially oriented will face some different challenges. For example, these children, as they get older, may wish to date, seek out sexual partners, marry, and have children. They may be grappling with issues related to sexual orientation, sexual responsibility, choosing appropriate birth control methods, and so forth. Their lives will bring them choices and responsibilities that the child or young adult with significant developmental delays isn't likely to face. However, those individuals will face many of the same problems in accessing accurate information about sexuality issues.

If your child is not significantly developmentally delayed, there are a variety of sexuality education curriculums and training materials that can be used appropriately. Ask your school program what curriculum they are using for their regular education students and also their students with developmental disabilities. We list several curriculums in chapter 10 that you may find useful. However, it is important to note

that these materials will require a good bit of adaptation for many children and young adults with deaf-blindness. Most of them rely on pictures, videotapes, models, and other visual/auditory materials that may be difficult or impossible for the student to access with limited vision and hearing. Additionally, extra attention should be paid to concept development when using these materials. As we know, the deaf-blind child may have missed absorbing many of the key concepts needed to understand these lessons, even those students with average and above-average intelligence. It is a good idea to work with your deaf-blind specialist, teacher of the deaf and hearing impaired, and/or teacher of the visually impaired to make appropriate modifications to these programs.

Why Is It Important To Address Issues Related To Sexuality?

One topic that is often difficult for most parents (and even most professionals) to think about is the sexuality of a child with deaf-blindness. This is especially true when the child is young or if he or she has significant developmental delays. Yet in our society, our sexuality defines who we are, influences how we are valued, and dictates in part the rules society expects us to follow in our day-to-day life. This alone is reason enough for parents to think about their child's sexuality. When the child is deaf-blind, there are even more reasons why this topic becomes a priority.

SEXUALITY IS A BASIC HUMAN RIGHT

Because our sexuality is such an important part of defining who we are, it is very important for us to have information and guidance about our sexuality. Deaf-blind children have the same right regardless of their learning style, age, or level of functioning. Just like their nondisabled peers, they have the right to enjoy and take pride in this part of human experience. Just like you and me, they have a need to give and receive physical love and affection.

CHILDREN WITH DEAF-BLINDNESS ARE NOT ASEXUAL

Deaf-blind children are not asexual simply because they are deaf-blind. Although some syndromes and conditions may affect sexual development and functioning, most of these children follow typical patterns related to the physical development of sexual traits and sexual drive.

What Are The Issues?

What are the issues that lead us to believe it is important to advocate for sexuality education that begins at an early age and continues throughout the school years and into adulthood for those with deaf-blindness?

SOCIETY'S ISSUES ABOUT SEXUALITY AND DISABILITY

- *We are generally uncomfortable about sexuality.*

Our society gives mixed messages about sexuality. We see sexual messages everywhere these days. They are used to sell cars, food, clothing, entertainment, and telephones. We can hear about the sexual escapades of famous people while watching television during our evening meal. Even with children, fashion and behavior have an underlying theme of being "sexy." Look around you. It is on the television, in print ads, and in the jokes told at the office or a party. Just about everywhere, there are messages affirming the power of sexuality.

At the same time, it is difficult for us to have frank discussions about appropriate sexual behavior with each other and with our children. We often do not refer to our reproductive body parts by name, but instead refer to them in clever (or not so clever) slang words. Despite a high rate of teen pregnancy and in the face of increasing rates of sexually transmitted diseases, many people fight to keep even non-disabled children and young adults from receiving sexual education and information about birth control techniques.

- *We are really uncomfortable with sexuality and disability.*

Sometimes it seems as if our society believes sexuality is tied to health, beauty, and a mythical physical perfection. Most of us buy into these perceptions even though reality and our own experience would tell us otherwise. The fact is, we all know that people who have chronic illness and who are not perfect physical specimens, are sexual beings. Nevertheless, these perceptions of the correlation of sexuality and physical perfection allow us to act as if people with disabilities are asexual. We frequently think of them as not having sexual urges or a need for physical love. We may even feel that they are not entitled to have meaningful sexual relationships, no matter what their disabilities happen to be.

We often act as if deaf-blind persons, especially those with significant developmental delays are completely different from the rest of humanity, and we do not give them the same respect we would give any other person. We may not afford them the same degree of modesty or personal space. "After all," we tell ourselves, "they can't tell if anyone is looking." We feel free to touch them in very intimate ways without asking their permission or giving them any control, and we do not often think about their need or desire for physical affection.

- *We judge harshly those who break the rules.*

Sometimes our notions about sexuality and disabilities have to do with rules. In our society, we judge harshly those who break rules about sex-

uality and sexual behavior. Unfortunately, most of the rules are unwritten, are not formally taught, are learned incidentally, and vary according to the age, situation, and culture. How do most men learn that it is not "cool" to choose the urinal next to someone if other urinals are available? They probably did not learn the finer points of bathroom etiquette from classes that were taught in school. Learning the rules about sexuality can be especially tricky for children with deaf-blindness and significant developmental delays who generally need to have the rules explained.

Society can misinterpret the natural curiosity of these children. This curiosity is often perceived as having a sexual nature. It may also be threatening because these children often rely on other sensory clues to figure out with whom they are interacting. Going into someone's personal space to touch, see, smell, or taste causes adverse reactions. Making physical contact with areas of another person's body that are considered "off-limits," is frequently perceived as a sexual advance. This is especially true if the deaf-blind individual is not a young child. If society has problems with an uninvited kiss, how will people feel about being licked or sniffed? The child may not have a sexual motive behind his or her behavior; still it can and often will be perceived that way by those not familiar with deaf-blindness.

Actions that are acceptable in a young child can be labeled "sexual assault" if carried out by someone who is older. When the deaf-blind person breaks one of the unwritten rules, people react strongly and often negatively. A young child can usually bestow an unsolicited kiss on a stranger without causing alarm. If he or she is a teenager or adult, there would be less comfort with that behavior. If an adult kisses a young child who is a stranger, he or she might be accused of being a pedophile or possibly charged with assault. At the very least, there would probably be a bad response from the young child's parents.

- *We are not certain how or when to provide instruction to children with deaf-blindness.*

As a society we are not sure who should provide sexuality education for our typical children. There is debate about how it should be provided and when it should start. Some people think this should be the responsibility of the family. Others think the church or the school should take on the job. Should we teach human development or should we talk about sexual relationships? Do we use films, books, and lectures, or do we take other approaches? Very young children have questions about their body and gender identity. Should sexuality education begin in preschool or wait until they are ten or eleven? If we are uncertain about sexuality education for a typical child, we are doubly so for the child with deaf-blindness and significant developmental delays.

When we do offer sexuality education classes or instruction, we seldom include children with severe disabilities. Or when we do include them, we don't generally take into consideration some of the basic concept development issues that they have. We are less likely to include instruction that will prevent these children from being sexually abused even though statistics show they are at high risk for abuse. We think, "Who in their right mind would hurt a child with these severe disabilities?" The answer is, of course, no one in their right mind, and possibly someone in that state who sees the child every day. Disability, especially when it impacts communication, cognition, and the child's ability to let people know about the abuse, makes the child especially vulnerable.

THE DEAF-BLIND CHILD'S ISSUES

- *Children with deaf-blindness and developmental delays do not learn incidentally.*

Much of what the average person knows about sexuality comes from informal or incidental learning sources. Deaf-blind children do not have access to the same amount or type of information as a sighted, hearing child. They often cannot successfully learn about their own sexuality in typical ways because of their sensory impairments.

Typical children learn every day of their lives, simply by observation, about behaviors that may be considered sexual in nature. They watch their parents and peers interact, read books, and watch movies and television where they learn about human sexuality and sexual behaviors. By observing the behavior of others and the reactions others have to those behaviors, most children develop rules related to their sexuality. They learn when and where these behaviors are considered appropriate. Feedback of this kind helps them to understand unwritten rules about personal space, touch, smell, personal questions, inviting or rejecting interactions, dating, parenting, public versus private behaviors, etc. Children with deaf-blindness and significant developmental delays simply do not have the same ability to access this information and make these same observations.

Typical children generally also receive informal instruction and modeling from family and others around them. One of the first language games many parents play with their baby is to ask them, "Are you a boy or a girl?" Most children engage in hours of pretend games where they act out different roles related to gender. They try on the roles of mommy or daddy, they compare body parts and establish rules about dress. Adults and peers shape their behaviors in a variety of interactions throughout every day. Children with deaf-blindness and significant developmental delays generally don t receive this informal instruction.

Typical children who are very young will have an awareness that people can see and hear them. As a result, they naturally develop a sense of modesty as they get older. They know about hiding and being seen. Non-disabled children will learn quickly about the difference between public and private behaviors. The constant shaping of their knowledge of appropriate conduct begins when they are just babies. It is normal for most children to have a deep understanding of the complex rules of behavior that guide day-to-day conduct.

Most deaf-blind children, especially those with significant developmental delays, don't have this same awareness. They may not even be able to see if other people are nearby. They may not know that a door or curtain needs to be shut. These children have to be carefully taught about public and private behaviors and they have to be given strategies for ensuring privacy.

- *These children may be confused by inconsistent feedback.*

Children with deaf-blindness and developmental delays frequently miss out on feedback from others. When they are given feedback, it is often confusing. A person may tolerate a child's hand as it moves across a face or an arm, but if it touches the breast or groin area, the person is likely to move away or push away the child's hands. How does the child know that we consider these areas of the body to be private? To him these areas of the body may be just more of the same thing.

The child is also likely to miss facial expressions, body language, or actual verbal feedback. These are the things that help a typical child know that his behavior is frightening or offensive to others. Many times strangers will show some anxiety in their face or their body may tense if the child moves in to touch or smell them. A sighted person may see this happening and perhaps try to prevent an unwanted interaction. The child, however, has missed the reaction altogether. He or she may not be aware of the change in the person's response until that response becomes very strong.

Many people who are unfamiliar or uncomfortable with people touching them or moving into their personal space feel threatened. They may not be aware that this child does not understand that this behavior is not acceptable. Responses may become physical, i.e., roughly grabbing the child's hand, slapping him or her, and so forth. Others may be confused about how to give feedback to a child with limited linguistic skills. They may choose to ignore or tolerate behaviors that are unacceptable. Feedback about these behaviors may be very inconsistent and confusing for most children with deaf-blindness and significant developmental delays.

Often we demand a level of behavior from the child that we may not be modeling. We may feel free to manipulate a child's body or touch him in incredibly intimate ways during caregiving routines, often without asking permission. How does the child learn the subtle points of sexually appropriate behavior, about modesty and appropriate touch, if these are the only models he is given? How can the deaf-blind child know that other people expect to be treated differently? If he cannot see or hear these behaviors happening around him and no one models these behaviors in their interactions with him, he cannot.

- *Generally these children take longer to learn new skills.*

As the parent of a child with deaf-blindness and developmental delays, you probably know that learning new skills requires more time for your child. Because this is true, it is critical to start earlier to prepare these children for future changes. Preparing a young girl for her first period should begin long before she is likely to start her period. It may start when she is very young by learning basic body concepts and vocabulary. Developing instructional routines that include a strategy for insuring privacy before undressing may take extra time and effort. However, if that is always part of the dressing routine, even when the child is quite young, it will be easier for everyone. Instruction in personal hygiene, appropriate social behaviors for adults, and so forth should be started early with adult outcomes in mind.

- *Children with deaf-blindness and developmental delays have difficulty changing established behaviors.*

It is generally more difficult to change the behaviors of these children than it is to establish appropriate behaviors initially. For example, it may be difficult for a child to shift from hugging everyone as a very young child to only hugging family and select friends when he or she gets older. Parents and professionals need to imagine how the children's behaviors will be tolerated when they are adults. Maybe it would be better to begin by teaching handshakes as greetings and hugs as ways to show affection for family and close friends.

- *These children use the tactual sense more often in learning.*

It is important to remember that touch is one of the primary teaching and learning channels for most children with deaf-blindness and developmental delays. This often creates problems for them in learning about sexual issues in two different ways.

First, deaf-blind children, especially those who have significant developmental delays, are accustomed to people touching them. People direct them by touch. They help with caregiving activities by physically guiding them, and they communicate with many of these children through touch. This makes it more difficult to teach about appropriate and inappropriate touch.

Second, if the child requires instruction through the tactual sense, teachers and parents may feel uncomfortable and vulnerable when explaining some concepts through touch. They may also simply not know how to adapt their instructional strategies to the tactual learner. If the child cannot have information presented in his or her preferred learning style, he or she may not be able to access the lesson.

- *Children with deaf-blindness get the wrong message when behaviors are ignored.*

Sometimes we are tempted to avoid addressing sexuality issues with children with significant disabilities and developmental delays. "If we pretend this is not happening, maybe it will go away." Sexuality issues do not go away. Lack of instruction can become instruction when related to sexuality. Ignoring sexual behavior and allowing the child to use inappropriate touch teaches the child that the behavior is appropriate and that there are no social consequences for it. Not teaching a child about sexuality and how to express natural urges in a safe and appropriate manner denies a big part of what is essentially human. Lack of knowledge creates vulnerability to pedophiles or others that would take advantage. We cannot rely on the child to learn about sexuality incidentally. That is why we need to provide instruction in an organized fashion. Instruction must also start at an early age to avoid problems when the child reaches puberty and transitions into adulthood.

- *Many children are not taught basic concepts.*

Children with deaf-blindness and significant developmental delays typically miss learning some of the basic concepts that are essential to understanding rules about sexuality. This is because we do not always provide systematic instruction to insure that certain vocabulary and concepts are taught. Concepts such as "boy," "girl," "private," "public," "alone," "friend," "stranger," and so forth may not be taught. We may not include vocabulary that includes terms such as "penis," "vulva," and so forth, instead choosing to refer to them as "potty" or "pee pee" or some other confusing term. We may work very hard to teach the child to use a restroom independently. We must ask if we spend an equal amount of time teaching "stranger" so, for example, a young boy will know not to approach the person at the urinal next to him for assistance with his belt.

- *Children with deaf-blindness need to be taught to participate in medical examinations.*

These children should be taught to participate in regular medical examinations such as pap smears or testicular exams. Otherwise, the exams will likely have to be done under anesthesia. All too frequently deaf-blind children and young adults with developmental delays do not receive regular medical exams for this reason.

ISSUES FOR THE PARENTS

- *Parents may have difficulty understanding and addressing their child's sexual behaviors.*

Parents often feel some confusion about sexuality and disability with their deaf-blind child. They may think in some instances that their child's sexual development will be delayed or that the child may not develop sexually because they are disabled. The reality is that most conditions or syndromes that cause deaf-blindness do not have any impact on sexual development.

Additionally, some sexual behaviors from the child are not acknowledged as being sexual. Instead parents view them as "deaf-blind behaviors." For example, even if it is obvious that the child is masturbating with the vibrating toy, the parent (or for that matter, the professional) may look the other way and not intervene.

Sometimes parents teach behaviors to their child that may take on a sexual connotation as the child matures. For example, they may teach their child to hug people as a way of saying hello or goodbye. This may be appropriate with family members or close friends, but when the child is older and perhaps working in the community this can create problems. Hugging strangers is not only inappropriate, but in some cases can become threatening. It may also be unsafe.

Sometimes parents allow behaviors they would not allow from a child without disabilities. They may not know how to prevent their child from exhibiting certain behaviors. If the child did not have a disability they would just tell the child to stop. Telling the child with deaf-blindness and developmental delays to stop a behavior usually does not work, and neither does using physical restraints or punishment. In fact, these may only lead to power struggles and an escalation of that behavior. Additionally, most parents have to work very hard just to get their child to interact with others. So when those inappropriate interactions occur, parents may be reluctant to stop or redirect them to more socially appropriate behaviors.

- *Parents aren't sure about what sexuality means for a child with this level of disability.*

Like the general public, many parents may have a narrow definition of sexuality. Because they perceive that their child is not capable of having sexual relationships, marrying, or reproducing, they assume there is no need for physical love or sexual expression. They tend to overlook the other aspects of sexuality such as gender identity, appropriate touch, modesty, and physical development. They view their child as different from other human beings in this area of development.

Some parents understand that their child will develop sexually and may seek out ways to express his or her sexuality. Still, they are not sure how to support their child in this area of development. How can they include their deaf-blind child in typical age-appropriate activities that allow him or her to explore sexuality? Parents may view providing instruction in sexuality as encouraging activities beyond the child's understanding.

- *Parents are considered to be the experts.*

Many parents feel that they lack the information and skills have needed to provide sexual education and support to their child; however, professionals often regard parents as the experts. Doctors expect parents to prepare their deaf-blind daughters for their first pelvic exam since communication is certain to be an issue for doctors. Schools expect families to tell them what to do about a son who masturbates or strips in public.

Parents are well aware of how harshly others may judge them and their child for these behaviors. They may have been told or instinctively feel that they should be able to stop inappropriate behavior. When they do not know how to provide needed sexual instruction, parents may feel pressure to use extreme measures. They may resort to restraints or physical punishments to prevent their child from acting out sexually in public places.

- *Some parents may be uncomfortable seeking help from professionals.*

Parents are frequently embarrassed to discuss issues of sexuality with professionals. Individualized Education Plan (IEP) meetings and teacher conferences often include many different players making it difficult for parents to feel comfortable bringing up the subject. The parents may also not be sure how their concerns will be treated.

- *Parents need to be sure that their values will guide instruction.*

Parents want assurances that their values will guide sexuality instruction for their child. If schools take on the task, consideration must be given to assure parents some control of information and how it will be presented.

- *Typically parents have concerns about sexual abuse.*

Issues about sexual abuse and their child are very real to most parents. Some parents fear that their child may be abused and will be unable to tell them what has happened. Unfortunately, statistics validate these fears. (See Chapter 9, page 94)

Others are afraid that their child will be accused of sexual abuse or sexual misconduct with others. In fact, some of the actions of the child could legally be considered assault, especially when the child enters

adulthood. While we would like to believe that the courts would choose not to prosecute these actions, there are no guarantees. Even if a deaf-blind individual avoided an indictment on a sexual charge, just being arrested would be traumatic for him or her and the family as well.

Many parents are aware that they may also be vulnerable to accusations of sexual abuse when their child acts out sexually. An accusation, even one that is unproven, can cause incredible damage to the family and the child.

- *Parents need to become aware of medical issues.*

Parents may not see the need for their child with deaf-blindness and additional developmental delays to have many of the regular medical checkups that their typical peers would have. For example, gynecological exams may not seem necessary if parents do not think their daughter will be sexually active. Unfortunately, many of the syndromes that cause deaf-blindness have secondary conditions that may go undetected. Obviously, individuals with deaf-blindness and developmental delays are at no less risk than any other individual for diseases or disorders involving the reproductive system. Without periodic checkups and tests, including prostate and rectal exams, pap tests, mammograms, and so forth, major medical problems can go undetected until the individual exhibits dramatic symptoms. By then it may be too late to achieve a good medical outcome with treatment.

Children with deaf-blindness generally will need a lot of preparation to undergo the usual medical examinations involving the reproductive system without being anesthetized. Since these children have often experienced many painful medical procedures through the years, this task can be quite daunting. Parents may not know how to prepare their child for these exams.

EDUCATORS' ISSUES

- *Some educators do not feel that sexuality education is a priority for instruction.*

When a child is deaf-blind, there is a tremendous need to focus on communication, concept development, orientation and mobility, functional skills, and motor development. Educators feel an urgency to focus on these more traditional areas of instruction and they often feel that instruction in the area of sexuality is not a priority. Even if it is not certain that a child will live independently or hold a job in the future, it is certain that he or she has a gender and will be a sexual being. For this reason sexuality education must be a priority for instruction.

- *Some educators may believe that instruction is not the school's responsibility.*

Frequently educators may believe that sexual education is the responsibility of the family and not the school. Sometimes teachers' personal comfort-levels, beliefs, and values may hinder them in their ability to address issues related to sexuality. Even when they do try to provide instruction, their approaches may not always be well adapted to meet the needs of the deaf-blind child with developmental delays. Their efforts often tend to focus on stopping behaviors rather than on supporting the child to appropriately express his or her sexuality.

- *Most educators lack appropriate training in providing sexuality education or curriculums for instruction.*

Educators sometimes feel it is easier to ignore behaviors and issues about sexuality. They are reluctant to provide instruction. This is especially true when they do not receive pre-service or even in-service training on providing sexual education to a child with deaf-blindness.

Most university training programs do not offer teachers-in-training instruction in providing sexual education to their students; therefore, many educators do not have knowledge of appropriate curriculum for providing sexual education. Sex education curriculum that has been developed for cognitively impaired or developmentally delayed individuals requires the use of vision, hearing, and a reasonably sophisticated language base. Teachers may not know how to adapt existing curriculum, especially for the child with sensory impairments and with limited or emerging linguistic skills and poor concept development.

- *Instructional strategies may require the use of concrete materials and tactual exploration.*

One of the more difficult aspects of providing sexuality education for this student is that of learning styles. Most of these students must be taught using real objects in real-life situations. Books, videotapes, rubber models, anatomically correct figures, and so forth may have no meaning for them. Additionally, the child may be a tactual learner. It may be uncomfortable for the instructor to present a tactually adapted lesson, and/or they may not know how to make the appropriate adaptations for the tactual learner. As Maurice Belote with the California Deafblind Project shared:

Instruction may require the use of concrete materials and instruction. This is one of the most difficult aspects of sex education for some students who are deaf-blind. It is not always possible to "talk around" a subject, or use abstract descriptions to provide instruction. For some students, instruction must be made very real. Clearly, most educational systems in most cultures do not allow the use of real people to teach issues of sexuality. . . . I think almost everybody who teaches this (certain sexuality education topics) *feels some anxiety when*

working with very concrete and/or graphic materials. . . . t's important for me to admit that I am far less comfortable doing this lesson than I am teaching anything else that is part of a typical school day.

- *Schools often lack formal policies and procedures to guide instruction.*

If there are five people in a room, there are probably five different ideas about what should be included in sexuality education and how it should be provided. Sexuality instruction touches on deeply held personal values and beliefs. For this reason, many schools do not have formalized policies and procedures. This lack of support impairs teachers' ability to implement sexuality education students who are deaf-blind and have other developmental delays. This situation creates confusion for the staff, the child, and the family.

- *Educators have concerns about sexual abuse.*

Frequently teachers and staff may have the perception that providing instruction in sexuality education makes them more vulnerable to accusations of sexual abuse. The reality is that educators may be more vulnerable to these accusations without a well-developed policy and systematic training. It is critical for schools to have policy and training about how to provide sexuality education to the children with significant disabilities including those who are deaf-blind.

Conclusion

Much of the future of this group of children may be uncertain. However, it is a certainty that they will always be either male or female. Their sexuality is one area that they definitely have in common with their non-disabled peers.

As parents and educators, we have a responsibility to meet their needs in becoming sexually competent. They have a right to experience this rich and important aspect of being human. We owe it to them to become knowledgeable about their needs in this area and to provide the support and instruction they require.

Our hope is that this publication will motivate and provide guidance to parents and professionals in the area of sexuality education for children with deaf-blindness and significant developmental delays. It is our belief that knowledge and caring intervention help them to be more fully included in the world. Sexuality education is a critical and frequently neglected area of instruction and we ask that you please learn all you can and start early to instruct your child about his or her sexuality.

Chapter 3

Developing a Process for Intervention and Instruction

There is a very low incidence of deaf-blindness among school-aged children in the United States. It is possible that your child or student is the only person with deaf-blindness whom you know. When we talk about developing a process for intervention and sexuality instruction for this one individual, the first question is probably, "Why? Can't we teach him like we would any other child with disabilities?" That is a reasonable question, but the answer has to be, "No!" What we are proposing here may seem like a lot of work and it is. In the long run, however, having a well-thought-out plan saves precious educational time. It also provides necessary safeguards to prevent negative situations which could rapidly become serious problems.

As we discussed in Chapter 1, a child with deaf-blindness and significant developmental delays faces unique challenges in learning about sexuality:

- He or she may lack many of the basic concepts related to body and behavior.
- He or she may be unable to learn incidentally the rules and information related to sexuality.
- These sensory impairments cause the child to miss out on informal instruction and modeling which are the ways most children society's rules about sexuality.
- The child may be confused by inconsistent feedback from others regarding his or her behavior.
- When behaviors are ignored, the child often gets the wrong message about expressing his or her sexuality.
- The deaf-blind child generally takes longer to learn new skills, which means instruction must start early with adult outcomes in mind.
- As the child ages or moves to different environments, he may have

difficulty changing established behaviors that are then perceived differently. Some of these behaviors may place the child at risk for being abused or for being perceived as a sexual predator.

- Without systematic instruction a child might not be able to participate in medical examinations except under anesthesia. As a result, he or she may be at greater risk for health problems.

As a parent or professional, you may not have the information about sexuality that is needed to provide support and instruction to the deaf-blind child. You may be uncomfortable with the task and may find it especially challenging to provide instruction to children who use the tactual sense as the primary channel for learning. You may have issues and concerns that tap into long-held beliefs and core values. As someone who wants to provide sexuality education to the child with deaf-blindness, you probably know that this is an important and difficult task.

The Process For Developing A Sexuality Education Program

A systematic process can help you and your school to work together to develop appropriate programming for your child. If your school does not have a process in place already, the process we offer might serve as a guide to your team in developing a program. Here are the basic steps:

1. Have the IEP team or a steering committee oversee the process of developing an appropriate sexuality education program.
2. Have the team (or committee) review and compile informational materials related to providing sexuality education for deaf-blind children.
3. Have the team (or committee) develop a draft policy and guidelines for instruction and intervention for staff and families to review.
4. Share the draft policy with all parents of students with deaf-blindness, the staff working with these students, and appropriate school administrators.
5. Have parents and staff complete needs assessments for deaf-blind students related specifically to providing sexuality education.
6. Revise and finalize the policy and guidelines for instruction and intervention based on the needs assessments and feedback from administrators, parents, and staff who reviewed the documents.
7. Develop permission forms and have parents sign them before instruction is provided.
8. Provide preliminary and ongoing training on sexuality education to parents and staff.

9. Develop the deaf-blind students' IEP's to clearly define specific instructional goals and objectives in the area of sexuality education each year.

STEP 1: FORM A STEERING COMMITTEE OR TEAM

The very first step that schools should take is to bring together qualified and interested stakeholders to help develop guidelines for sexuality education. Members of this steering committee should include family members, teachers, paraprofessionals, and one or more administrators. When developing the program for a single child, the committee most likely would be the IEP team. Some additional people may also be included: a school counselor, the school nurse, a family planning clinic representative or someone familiar with sexuality education, a deaf-blind specialist, and/or a representative of the medical community.

The IEP will guide instruction in sexuality issues just as it guides instruction in other areas for the child with deaf-blindness and developmental delays. This should be the case whether addressing the needs of a single child or of several children in a program. Educational needs should be determined through assessment and then appropriate goals and objectives developed. Support to the family should be outlined, and then staff training needs identified and planned.

There are additional factors related to providing sexuality education differentiating it from other areas of instruction, even for a single child. This type of education is a sensitive topic for both family and staff, and there is often a tremendous lack of knowledge about providing sexuality education to deaf-blind children who have significant developmental delays. Legal actions are likely to happen if situations are not handled appropriately. For these reasons, we strongly recommend the establishment of a formal steering committee to oversee the process of providing sexuality education.

The committee's tasks should include:

- Reviewing and compiling articles, instructional materials, and existing school policy related to providing sexuality education;
- Developing and conducting a needs assessment of the child(ren)'s family(ies) and educational/support staff related to providing sexuality education;
- Developing a document that contains both policy and guidelines for intervention and instruction;
- Insuring that adequate training for providing sexuality education is made available to the staff and families.

This may seem like an unreasonable amount of work for one student, but it is important. The work done by this group will guide educational practice for a child's entire school career and will also serve the school as other students with deaf-blindness move into the system. The work may be needed because one child turned up in a classroom this year, but it can be used for many children and for years to come if it is regularly reviewed and updated. This kind of effort helps to insure that sexuality education becomes a standard part of the curriculum for every child with deaf-blindness.

STEP 2: REVIEW AND COMPILE EXISTING LITERATURE AND CURRICULUMS

It is very important for your group to become familiar with existing literature and curriculum related to providing sexuality education. In the final chapter of this book, we offer some suggestions to help you begin this exploration. You may also want to search out resources in your own school and community. Even if they are not specifically designed for this group of children, they will help you anticipate issues and develop instructional resources and strategies.

STEP 3: DRAFT POLICY AND GUIDELINES FOR INTERVENTION AND INSTRUCTION

What is policy?

Policy is an established and approved set of statements meant to inform and guide staff and family members about how programming and intervention will be provided. Policy should set the ground rules about how formal instruction is to be offered and should aid in the development of the IEP. It should also guide moment-to-moment decision-making in intervention. As you begin to write policy to help family and staff address issues of sexuality education for children with deaf-blindness and developmental delays, make sure the following issues are addressed:

- *Deaf-blind students have the right to receive sexuality education.*

The policy your team develops should validate each student's right to have appropriate sexuality education as determined by the IEP team. IDEA states that schools "shall take steps to insure that ... children with disabilities have available to them the variety of educational programs and services available to non-disabled children." (CFR 34 §300.305 IDEA 1997, Subpart C). If your school is not providing education in sexuality to your deaf-blind child, it should be.

You may think that your school district or program does not offer sexuality education to any of its students. Even though there may not be a course with that title, instruction in this important area does take place

in every school to some degree. For example, in kindergarten, typical students learn to name and identify body parts, gender roles, and how to avoid or report being approached inappropriately by strangers. This is the beginning of sexuality education. As typical students progress through the grades, they are introduced to concepts related to reproduction, social rules, relationships, and parenting. These may be taught as part of a science, social studies, or home economics class. These ideas that are so important for typical students to learn are just as important for deaf-blind students. Even when children have significant developmental delays, basic concepts are important to learn despite the fact that they may not be able to master more complex issues.

The book *Blind and Visually Impaired Students Educational Service Guidelines* published by the National Association of State Directors of Special Education, gives guidance on best practices for students with visual impairments. In discussing social and independent living skills development, it notes "blind and visually impaired students cannot learn these skills without direct, sequential instruction by knowledgeable people" (Pugh and Erin 1999, p.179). Assessment should be done to identify the social skills and independent living skills individual children must develop to achieve success as an adult. You should begin at the earliest point in your child's schooling to include goals in the IEP to insure instruction in these important areas, many of which are the basis of sexuality education.

- *Be sure the policy you develop does not contradict existing school policy or law.*

Does your school have a policy about providing sexuality education? Does your school offer a specific course of study for students or is sexuality education included in other classes such as home economics, biology, social studies, etc.? Review your school's existing policy related to providing sexuality education and use it as a basis for developing your policy. Find out how typical students learn about sexuality in school. It is critical that administration supports the sexuality education policy that your team develops.

Your school will also have policy about staff and student behavior and you will need some of this information as a basis for developing policy. If the policy you set differs from other related school policy, you need to be prepared to explain why. For example, a typical student who strips off his clothes may be subject to expulsion or assignment to an alternative campus. This is an inappropriate consequence for the student with deaf-blindness and developmental delays. For that reason you may need to include in your policy the provision that specific behavior plans can be developed as part of the students' IEP's to address exceptions to regular school policy.

You should be sure that there is no conflict between the policy you establish and any laws. For example, there are very specific laws about reporting suspected sexual abuse. You should make sure your policy does not contradict steps that are required under the law regarding this issue.

- *Good policy establishes a clear chain of command.*

It is very important that the policy you develop establishes an appropriate and clear chain of command to address situations that arise. It should also answer questions and address concerns from family and staff. For example, if a student inappropriately touches another student, does the paraprofessional need to document the incident in some way, report it to the teacher, send a letter home to the families, or what? Being clear about how situations should be handled before they occur makes staff and family feel more secure. It also reduces the likelihood of the mishandling of situations.

As we noted earlier, there are specific laws about dealing with suspected sexual abuse. Your school will have information about who should be called in and about the staff's responsibility to report suspected abuse. This information should be a part of, or be referenced in, your policy. Training about reporting sexual abuse should be part of the regular in-service scheduling each school year.

- *Good policy requires staff training before instruction or intervention is provided.*

One of the best safeguards related to providing quality sexuality education is training. It is important that your policy clearly states that staff will receive specific training before carrying out certain intimate caregiving tasks and instruction or intervention related to the child's sexuality. If they don't know how they are expected to handle certain situations, it is likely that mistakes will be made. This is traumatic for the child, the parents, and the staff. It also can lead to serious legal consequences.

- *Good policy reflects information gathered from needs assessments.*

When you share your draft policy with staff and families and review their needs assessments, you may need to make revisions and updates to policy. Each year or so, the committee should conduct additional assessments to make sure that policy addresses the changing needs of the families and staff. Below we give an example of the policy section of the document. Your team may want to begin with this sample policy and modify it to meet local needs.

A Policy for Providing Sexuality Education to Students Who Are Deaf-Blind

1. School district policy pertaining to sexuality education, as outlined in the employee handbook, will be followed. [INSERT LOCAL SCHOOL POLICY.]
2. State law and school district policy will be followed in addressing and reporting suspected sexual abuse. [INSERT LOCAL POLICY AND STATE LAWS.]
3. The issue of sexuality education will be discussed as part of each student's annual IEP process until he/she leaves the educational program.
4. Any instruction or intervention provided by the educational staff in the area of sexuality must be within the bounds of the student's IEP.
5. Existing school policy regarding sexuality instruction may not address special factors that exist for a student with deaf-blindness. Therefore, any necessary variations from regular school policy must be approved by the IEP committee and documented in a formal behavior plan and/or the student's current IEP.
6. Appropriate deaf-blind modifications should be made in sexuality education strategies and materials to insure that the student who is deaf-blind can access instruction.
7. Every effort will be made by staff to insure that the family's values will be honored in providing intervention and instruction as defined by the child's individual educational plan (IEP).
8. Any student who is receiving instruction in the area of sexuality must have written permission from his/her parent or guardian. (See attached permission form.) This permission form must be kept in the student folder and renewed annually.
9. Any questions or concerns from the staff or family regarding sexuality instruction should be documented in the student's file and brought to the immediate attention of the principal and special education supervisor.
10. Any incident of a sexual nature that causes concern should be documented in the student's file and brought to the immediate attention of the principal and special education supervisor.
11. An administrator and classroom teacher will notify parents by phone or in writing at the earliest opportunity about instructional concerns or incidents related to sexuality.
12. To be fully prepared to meet the needs of the student and his or her family, all staff having direct contact with the students will be required to participate in sexuality education training prior to providing instruction to the student with deaf-blindness.
13. A needs assessment will be conducted annually with staff and the family to pinpoint the topics for training in sexuality education.
14. The staff serving the student with deaf-blindness should review the IEP goals related to sexuality instruction prior to completing the annual needs assessment.
15. The program's policy on sexuality education for students' with deaf-blindness will be reviewed annually by a designated school administrator. Sexuality education policy will be revised as needed to support effective and appropriate intervention for students who are deaf-blind.

What are Guidelines?

After completing the policy section of the document, your team will need to develop the guidelines for instruction and intervention to assist staff and families. General guidelines should cover all topics of instruction. They should define the areas of instruction and describe in broad terms how instruction should be approached. Below we offer nine general guidelines that we recommend should be in your document. Other chapters of this book addressing appropriate touch, masturbation, menstruation, sexual health, and sexual abuse, will contain additional guidelines that relate to each topic. It may be helpful to include these in a more topic specific portion of the guidelines. Your team will probably come up with some additional items not covered in this book, based on your school's individual situation and needs assessments.

Summary of General Guidelines for Sexuality Education of the Student with Deaf-blindness and Significant Developmental Delays.

1. *Sexuality education for the deaf-blind student who has developmental disabilities has a somewhat different focus than that of a typical student and must address more than the topic of reproduction. It should focus heavily on developing concepts and building skills in accord with basic rules of social behavior as well as on instruction about appropriate touch and personal boundaries, modesty, menstruation, masturbation, sexual health, and sexual abuse.*

Children in this category need much more than typical sexuality education programs provide. Concept development may be overlooked, and certain topics may not be covered. The focus on basic rules of social behavior is key for these students because they generally do not learn them incidentally. Also, some such as masturbation, appropriate touch and personal boundaries, and modesty may not normally be covered in any detail in a typical sexuality education program. These students need instruction in these areas. Although reproduction may be part of the instruction for some students, many deaf-blind individuals with significant developmental delays are much less likely to be dealing with issues of dating, marriage, and parenting.

2. *When providing information in the areas of sexuality education, think in terms of four basic approaches to instruction: routines, units, teachable moments, and behavior plans.*

For most students with deaf-blindness and significant developmental delays you can organize the information you want to share in a structured routine. A structured routine has a clear beginning and ending, a logical sequence of steps, and specific locations and materials. Routines provide consistency and repetition which establish good habits. These children typically do not have to understand the social significance of something in order to learn to do it automatically.

Some of these students may benefit from information delivered through instructional units. Units emphasize practical experiences, giving children the concepts they are missing. They also tie this experience to language that the children need to discuss the information with others. Units are effective for students who can categorize and who already have the ability to represent information in an abstract manner (e.g. drawing pictures, signing, printing).

For any student you can seize incidental teachable moments to give information. This is a rich opportunity to highlight a behavior in context. Instruction is typically more effective because you are addressing a particular behavior or situation as it actually happens.

Sometimes a behavior has become entrenched and has proven to be detrimental to the child. When this happens, your team should develop a formal behavior plan. A behavior plan typically has the following components:

- a clear description of the behavior to be addressed;
- a list of events or conditions that precede the problem and should be avoided;
- a course of action when the behavior occurs;
- a process for collecting data to evaluate the effectiveness of the intervention;
- a way to document the incident in the student's file.

3. *Instruction and intervention should be consistent across caregivers.*

When you have developed an instructional strategy or intervention plan, it is very important to share it with all of the child's caregivers. Everyone needs to understand what is expected of both the child and the person interacting with the child. The more clearly everyone understands exactly what is supposed to happen, the better. If people are not clear and in agreement about instruction and intervention, the child will receive conflicting responses to the same behavior throughout the day. This complicates his or her learning and can have disastrous results.

4. *Don't overreact. Be calm and firm when you intervene.*

Overreacting is a temptation, especially when an embarrassing incident occurs in public. Emotionally charged reactions can cause serious problems in intervention. The child will usually know you are agitated, and this can cause him to become upset as well. It will be much more difficult to redirect the child, and the situation will take longer to resolve. If you stay calm, you will do a better job of implementing an existing plan or inventing one on the spot.

Some students enjoy watching the panic of their caregivers. They begin to do the behavior on purpose just to get a reaction. It is important to remember that overreactions can cause a single unintentional act to become an ingrained behavior. Many a good teacher has taught some really bad behaviors by overreacting.

If you remain calm and purposeful, you will be less likely to draw a crowd. The general public needs to see that you are in control. Your calm response will be reassuring and the situation will be less likely to escalate, drawing in the authorities or resulting in you and your student being asked to leave.

5. *Recognize that if you fail to react to unacceptable behavior you teach the child that the behavior is acceptable.*

When you know you are supposed to intervene, don't ignore a situation because you are embarrassed, tired, or afraid to start something. By not intervening, you are giving the child the message that what he is doing is acceptable. Not only that, you are giving him extra practice in carrying out the behavior. The next time it occurs and someone does intervene, the child will get a message that conflicts with the one you gave him. This is confusing and creates more problems for everyone.

6. *If possible, when working with young deaf-blind children who are also developmentally delayed, make sure that the skills they learn will still be appropriate when they are older.*

Remember that each student will grow up and the expectations of others will change as he or she matures. So, think ahead. If you are teaching preschoolers to greet a friend or a classroom visitor remember that this is the way they will probably greet a person when they are thirty years old. When you teach a boy to share a urinal with his preschool classmate, imagine what will happen if he tries this at twenty with some stranger in a public restroom. Instruction needs to have a future focus with clear adult outcomes in mind.

7. *Preserve the dignity and privacy of all students with deaf-blindness during instruction and caregiving activities.*

As you work with students with deaf-blindness and developmental delays, you will meet some who seem completely unaware of what is occurring, even in the context of a routine. The less awareness a student demonstrates, the more responsibility caregivers have for protecting and honoring the child's dignity and rights. This is true even if it takes more time and effort.

8. *Be mindful to redirect rather than confront.*

Be aware of what is happening in the environment and what the child is

doing. It is better (and generally easier in the long run) to be proactive and redirect a potentially problematic behavior. Once a behavior has started, it becomes difficult to stop it. One of the best rules of thumb is to distract the child rather than force a confrontation.

9. *To the greatest extent possible, reduce the risk of a student with deaf-blindness and developmental delays becoming a victim of sexual abuse.*

Accept that they are potential victims and supervise the children and those who have contact with them accordingly. To whatever extent possible, teach children with deaf-blindness skills that will help prevent abuse.

STEP 4: SHARE THE DRAFT POLICY

When you have the draft documents of policy and guidelines written, send them to both parents and educational staff. This will help to begin the discussion you must have in order to revise policy and guidelines and determine training needs.

STEP 5: CONDUCT A NEEDS ASSESSMENT

Some of the things you want to learn from your needs assessment are listed below.

- What do parents and educators see as instructional needs of the child(ren) in terms of sexuality?
- What are their priorities for instruction?
- How are the parents and educators currently intervening or providing instruction to the child(ren) related to sexuality issues?
- How do the parents and educators feel about addressing sexuality issues with the child(ren) with deaf-blindness?
- What training needs do parents and educators have in order to provide sexuality education to deaf-blind children?

Keep the needs assessment ***brief***. Mailing it out to the parents is an option but it may need to be shared with them in a face-to-face discussion.

Be sure the assessment is translated into the parents' native language. A school counselor, social worker, or the representative from a family-planning clinic may be able to advise your group on specific wording that will be culturally sensitive.

In many instances parents and staff will show a great degree of relief that someone is bringing up this issue and be eager to complete the assessment. Generally they will be very supportive of your efforts. Of

course, sometimes the parents and educators may be reluctant to respond to the needs assessment. Their lack of enthusiasm could be telling you that they aren't sure how to provide instruction or that they don't think the child needs instruction in sexuality. These are common issues for both parents and professionals. It is important to understand their perspectives and to address their concerns in order to develop the policies and guidelines that will serve as the foundation of instruction. It may be necessary to follow up in person with family members and staff to get the necessary input. Below we show a sample needs assessment for parents and educational staff.

Parent and Staff Sexuality Education Needs Assessment

1. We would like to learn more about your knowledge, needs, and concerns related to providing sexuality education to your child (student) who is deaf-blind. Below are some concerns common to parents (educators). Please check all areas that are of concern to you. You may wish to place a star or highlight topics that concern you the most at this time.

- ❑ Modesty (inadvertently exposing themselves in public bathrooms/dressing rooms, adjusting underwear, stripping, etc.)
- ❑ Masturbation in public ❑ Masturbation at home
- ❑ Menstruation
- ❑ Participation in medical exams (pelvic exams, testicular exams, breast exams, etc.)
- ❑ Pregnancy ❑ Birth control
- ❑ Sterilization ❑ Wet dreams
- ❑ Inappropriate touching of others (hugging or kissing strangers, touching another person's breasts or genitals, etc.)
- ❑ Dating/marriage ❑ Coupling
- ❑ Sexual abuse ❑ Other _____

2. Are you concerned about the future in terms of your child's sexuality? Why or why not?
3. What instruction has been provided to your child (student) related to sexuality? Was this provided by you or by a school program?
4. Do you think that sexuality education is the responsibility of the family, the school, or both?
5. Ideally, how early should sexuality education begin?
6. Do you need training about providing sexuality education for your child(student)? Specifically, what topics most interest you?

STEP 6: ADMINISTRATION, STAFF, AND FAMILIES REVIEW THE POLICY AND GUIDELINES

It is critical that the policy you write has the full support of the highest levels of the school's administration. When you have completed a draft of this document, we recommend that it be sent to administrators for comments.

You should also share the final version with pertinent staff and families. If there is only one deaf-blind child in your school, his or her family and some of the child's educational staff should have had a hand in developing the document. In later years, however, families that have not been a part of the initial development process (as well as new staff) should have the opportunity to review these documents and offer comments to guide revision.

It is important to hear feedback from these key people about the policy and guidelines you develop since they are the ones who will be most directly involved in implementing it. If they are not comfortable with what your committee has set up, the documents will not be used.

Of course, situations that no one anticipated and for which there is no written policy or guideline do occur from time to time. This is to be expected and is just another reason why policy may periodically need to be revised.

STEP 7: PARENTS SIGN A PERMISSION FORM BEFORE INSTRUCTION IS PROVIDED

It is a good idea to have the child's parents sign a form giving permission for their child to receive instruction in the area of sexuality. This should be done after they review the policy and guideline documents. The form should note that they have reviewed the documents and give permission for instruction. It might also include a place for parents to note what specific areas of sexuality instruction they will and will not approve of for their child. Of course, this permission does not supplant the IEP as the place for documentation of specific goals in the area of sexuality instruction. The following is an example of what a permission form might look like.

Permission for Providing Sexuality Education

❑ I have reviewed Kern Elementary School's sexuality education policy and guidelines. I have also discussed any questions I have about these documents with school staff. I give consent for staff to provide sexuality education to my child in accordance with this school policy and my child's IEP.

Please note: *Listed below are issues that may not be addressed with my child at this time. I would like to be contacted immediately if these issues come up incidentally.*

❑ I do not give my permission for sexuality education to be provided to my child by Kern Elementary School staff.

_____ _____

Parent Signature Date

STEP 8: PROVIDE TRAINING TO THE STAFF AND FAMILY

The policy and guidelines should clarify the program's approach to providing sexuality education for the child with deaf-blindness and developmental disabilities. They should also help with decision-making and insure that issues are addressed systematically year after year. So after these documents have been developed, reviewed and finalized, it is important to provide training to staff and families in order to effectively implement them.

The instructional staff will need an opportunity to clarify the intent of the policy and to ask specific questions about the instructional guidelines. Staff members responsible for providing sexuality education need to receive training in facilitating and implementing instruction that is in accordance with the policy and guidelines that have been established. They will also need assistance in accessing resources and instructional materials.

The parents will have training needs as well. They should be encouraged to review materials and observe instruction. Parents need to understand their role in supporting instruction since many "teachable moments" are likely to occur outside the school environment. Their in-

put into the content of the classes is expected, and their support is essential to success. Parents need to understand that no student will take part in these classes without the consent of the parent. Parents should also be assured that they have the option of allowing their children to attend some classes and not others as determined by the IEP process.

The steering committee or team should compile curricular materials, articles, and resources for staff and parents to use as a basis for instruction. They should make available a variety of in-service training options (including articles, videotapes, and so forth) on sexuality education. In addition to the initial training on policy and guidelines, there should be on-going training and support for the staff and families to address specific issues, such as masturbation, sexual health issues and medical examinations, managing menstruation, and sexual abuse.

The training may be provided in a variety of ways and by a variety of people. For example, reporting sexual abuse might be a topic that is addressed by the school's human resource staff, someone from Child Protective Services, a school administrator, or special education supervisor. Articles on menstruation management, testicular exams, or other topics may be shared through newsletters or during parent and teacher conferences. Videotape materials might be available through the school library for staff and family viewing. Taping lessons with the child or routines at home may be a way to cross-train on an individual child's specific instructional approach.

STEP 9: DEVELOP THE CHILD'S IEP GOALS

The process is not complete until a child's IEP has been developed. Staff and family on the child's IEP team must, of course, assess the child's needs by focusing especially on modesty, appropriate touch and personal boundaries, masturbation, menstruation, sexual health, and sexual abuse prevention. Typically a child will have needs in most of these areas each year. Look at skills that typical peers may be working on in the areas of socialization, relationships, human reproduction, and so forth. Identify priority areas for instruction, and develop appropriate goals for each area.

Conclusion

Clear policy, specific guidelines for instruction and intervention, and appropriate in-service training for staff and family are essential for providing sexuality education to the child with deaf-blindness and significant developmental delays. They help to avoid confusion and reduce conflict among staff and the families of these children. Good policies and guidelines reduce the risk of real abuse and suspected abuse. These steps help insure that the family can support programming that is provided in school. Training helps staff and family to develop appropriate

IEP goals. It also aids in developing instruction and assuring opportunities to practice new skills in both the home and school environments. A comprehensive approach to sexuality education may take more time, but it assures success in providing sexuality education to this population of children.

References

CFR 34 §300.305 Individuals with Disabilities Education Act, 1997 – P.L. 105-17.

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Chapter 4

Modesty

Society has widely standardized and highly ritualized rules about modesty: the how, when, where, and why of exposing specific body parts. After a certain age, one is clearly expected to know which behaviors related to modesty are allowed in public and which behaviors are considered private. For example, in most parts of this country, it is generally understood that one should leave the house each morning with certain body parts covered. There is a high degree of compliance, not just because of laws but also because of social acceptance and approval.

Modesty is extremely valued in our culture, even in these days when it seems that almost anything goes. As a member of society, one understands that certain things are "just not done" when someone is watching. Modesty has a higher value than comfort for most of us. One will endure binding underwear or panty hose that are uncomfortably twisted until a safe spot is found to make a quick adjustment.

Vision and hearing play a critical roll in preventing the violation of rules of modesty. If a restroom stall can't be located for the adjustment of those twisted panty hose, a woman would get creative. She may duck into a deserted part of the office, hide behind a door, or try to discreetly make the adjustment in the privacy of her car. She would rely on vision and hearing to avoid being seen by others and to avoid violating the rules about modesty.

Growing up, one learns the rules of modesty by watching others and by the way one is treated. One begins to understand the subtlety of rules that vary with age and with situation. It might be fine to run around the yard in a diaper at two or three, but running around outside in underwear at fifteen would be upsetting to others. Even though a swimsuit covers the same amount of the body as underwear, one learns that it's not proper to swim in the public pool in underwear after a certain age. For the child with deaf-blindness and significant developmental delays, rules about modesty are very difficult to grasp.

Issues About Modesty For The Child Who Is Deaf-Blind

RULES OF MODESTY MAY NOT BE LEARNED INCIDENTALLY

Deaf-blind children who are also developmentally delayed may not get enough information to learn the rules of modesty incidentally because of their vision and hearing losses. They do not have the opportunity to observe the way people are dressed in public versus the way they are dressed in private settings. They do not see how people respond negatively to immodest behavior. Most of the rules that typical people practice related to modesty are not formally taught, but rather are learned incidentally. Children with deaf-blindness do not have access to this form of learning.

Children in this group are very innocent about their bodies. They may respond to discomfort, environmental triggers, or boredom by removing their clothes in places that are considered inappropriate. They do not know that they should be embarrassed or feel shame about exposing specific body parts in public.

AWARENESS OF THE ENVIRONMENT IS OFTEN LACKING

Deaf-blind children may not always be aware of the environment (open curtains, doors) or of the presence of others. They may not know that the room has a window without a curtain or that the door to their bedroom is open to the hallway. If someone comes into their private space and does not inform them, the child may be unaware of their presence.

CARETAKERS DO NOT ALWAYS RESPECT THE CHILD'S MODESTY

The people who support deaf-blind children may not respect their modesty to the same degree as they would typical peers. Without meaning disrespect, they may be more inclined to leave a child disrobed in a public place such as a classroom. They might leave the stall door open to the toilet while they supervise several students during bathroom time. Children without disabilities protest such treatment at a very early age. These children insist on being treated with more respect. Children with deaf-blindness and developmental delays may not demand that same level of respect.

INNOCENT BEHAVIORS CAN BE PERCEIVED AS BIZARRE OR THREATENING

Though children in this group may be innocent in terms of modesty, they may still be guilty in the eyes of the public. If their behavior is immodest, they may be considered bizarre or threatening to many people. Immodest behavior can result in dire consequences for the children or young adults. After all, there are clear laws that allow people to be arrested for exposing themselves in public or for behaving in a way that

might be described as lewd. Even though these charges might not hold up for a person with developmental delays, the consequences could still be traumatic.

Guidelines For Instruction and Intervention

SET UP RULES AND ESTABLISH BEHAVIORS THAT WILL LAST A LIFETIME

Children with deaf-blindness and developmental delays may have great difficulty changing established behaviors. When they learn to do an activity a certain way or with certain materials, changing the routine is almost impossible. Often these children and young adults are considered "ritualistic" in their approach to life. This is why it is important to set up rules of modesty that will serve the children into adulthood. Unlike their typical peers, they will not be as easily shaped by peer pressure and society's approval. They may not "outgrow" certain behaviors.

To prevent the entrenchment of behaviors, make rules about keeping specific body parts covered outside the bathroom or the privacy of the bedroom. This involves extra work for you early in the child's life. Getting a pair of pants on him before he leaves the bedroom or making sure she doesn't undress in the living room might seem silly when the individual is three, but it isn't silly when he or she is thirty.

SHOW RESPECT FOR THE CHILD'S MODESTY

- *Model respect for modesty.*

From the very beginning of your child's life, model respect for his or her modesty. Dress your child appropriately when he or she is out in public, even if it takes a little longer. Refrain, as much as possible, from changing diapers in places other than restrooms or areas that are not private. Don't pull down your child's pants in the classroom to show the physical therapist where a brace is rubbing if there are other children and people around. Go to the restroom or find a screen to place between your child and the public's view.

- *Require others to respect modesty.*

Beyond modeling respect for your child's modesty, you must require the respect of others. Your child may not be able to tell a teacher or a therapist not to leave him sitting in the nurse's office without pants while they give another child an aspirin. You will have to be an advocate for the child. Educational teams should take some time to consider practices that fail to address modesty issues for children and set standards for staff practice.

ANTICIPATE PROBLEMS AND TEACH STRATEGIES FOR COPING

- *Be aware of environmental triggers.*

Many children with sensory impairments and developmental disabilities associate actions with specific things in their environment. For example, if a child showers, he may associate anything that sprays water with bathing. When he passes the sprinkler in a neighbor's yard, he may think, "Hey, it's time for a shower!" If a shower is one of his favorite activities, he may strip off his clothes and look for the shampoo. To prevent this, plan your afternoon walk to avoid the neighbor's yard while the sprinkler is on, or at least be prepared to head off an attempt to undress by talking about "waiting" for a shower.

- *Think about comfort.*

Most people have had the desire to shed uncomfortable clothing in places where one can't do anything about it. Unlike most people, children in this group may not have the same self-discipline. If they are uncomfortable in a garment, chances are good they will take the garment off. This is also true of things like sanitary pads. (See chapter 6, page 57).

One way to avoid stripping is to determine which clothes are comfortable for your child. It is important that you understand that this will be different from child to child. Some kids like soft, fuzzy clothes, while others like light, silky fabrics. One child needs things that fit tightly, while another wants things that are loose. For example, one girl liked to have the elastic of her underwear tightly around her waist and legs. She would pull the underwear up two inches above her pants just to get the sensation of having them cinched to her body. This was, at the time, not an acceptable fashion statement. The solution was to buy underwear with wider elastic around the waist and legs so she could feel more pressure against her body.

- *Complicated clothing can sometimes help.*

Even as you work on independence in dressing, you must sometimes pick clothes that are more complicated to get on or off. Some of these children may be prone to removing their clothes at inappropriate times and places. You may find it helpful to slow them down so you have more time to notice and intervene. Save the sweats for relaxing around the house. When it is time to go out to the mall or to a restaurant, think about clothing with buttons, zippers, and belts. Sometimes the only way to work on modesty is to prevent the child from easily being immodest.

- *Use calendars to help teach the concept of "wait."*

One word that you can use to head off a child who is starting to strip is "wait." The time concept of waiting is very helpful because it affirms

the child's need to do something while letting you have some control over when and where it will happen. You have to purposely teach the concept of "wait." One way this can be done is through the use of calendar systems. "Wait" is typically the second time concept you teach, "finish" being the first.

"Wait" should mean, "This event will happen later in the day." A child might find three symbols in his calendar box, and the third one is his beach towel. He loves to swim and knows that he needs to change into his swimsuit to do this activity. But because he has the symbols for work and gym in line before his beach towel, you can give him the sign for "wait" as you talk about what happens before he goes swimming. He will "wait" with his clothes on, first for work, then gym, until it is time for swimming.

A calendar box contains symbols that represent routines. A calendar gives a student multiple opportunities to take a symbol and head to a particular destination to complete the routine. The child learns there is some distance and time between picking up the symbol and starting the first step in the routine. Using the sign for "wait" in this situation means "You are ready to do something, but I need you to hang in there a few more minutes until we get to where this activity is going to be done."

Some children are not ready for a calendar system. However, they may still need a cue to acknowledge their need and to help you gain time to prepare for what they want to happen. The first step is to immediately acknowledge the problem to the child. For example, the child starts to pull off his shirt because he is hot. You might let the child know you are there and that you see that he is focused on a problem with the shirt by simply pulling at the fabric with him. You might say or signal something like, "shirt off" or "shirt hot." Secondly, you pair a cue for "wait" with that acknowledgment. The cue might be the sign for "wait" because of its distinctive appearance and feel. It could also be something else like firm pressure on the shoulder or patting the chest. Then try to redirect his attention or respond to his discomfort by fanning him or letting him put a damp cloth on his neck for a few minutes. Over time the child may begin to make the association with the cue and a delay in getting his needs met. In teaching modesty, this can be a critical concept.

TEACH THE CONCEPTS FOR "PRIVATE" AND "ALONE"

There are several reasons why these words are important in teaching modesty. These words establish some broad categories for the rules about modesty that society has set up. These basic concepts can help children to learn "rules" for their behavior as well. The first sign and concept that is taught should be "private." It means others can't look or others can't touch. Teaching the concepts for behaviors that are excep-

tions to the usual tendencies of the child are the easiest. So if a child starts to disrobe in the mall tell him "no wait private." When you are at home, help him to know he is in a "private" place by having him close his door and pull the curtains before undressing. Emphasize that no one can see him. Expand the "private" concept to body parts and personal items that others can't touch. Later you can expand the concept of "private" to talk about "alone."

"Alone" can mean, "no one is watching who will care what you do," as well as, "no one is present."

Some children will be able to grasp this concept, and others will only be confused by it. For example, sometimes you may be in a place such as a classroom that is not normally "private." Because no one is there with you and the door is locked, you have a temporary "private" space. But, the bedroom is only private if you are "alone" in it and the door is closed.

In some instances you might want to actually teach the concept "public" if the child has a thorough understanding of "private" and "alone." Most children with developmental delays will do better just focusing on what are "private" behaviors and places.

DEVELOP ROUTINES THAT BUILD IN "MODESTY" FEATURES

The goal of a routine is that the child will follow a set of "rules" even if he or she does not have a true understanding or awareness of why the rules exist. A structured routine has a clear beginning and ending, a logical sequence of steps, and specific locations and materials. Routines provide consistency and repetition, which establish good habits. A child with deaf-blindness and developmental delays doesn't have to understand the social significance of something in order to learn to do it automatically.

In developing routines, use a predictable and unbroken set of steps that does not vary from time to time. Make sure the steps of the routine that address modesty are never skipped. For example, a first step in a bathing routine might be to assist the child to close doors, pull curtains, and make sure no one else is in the bathroom with them before they begin to undress. If you have a big family, this may seem extreme and difficult to accomplish. However, when the child is an adult living out in the community, you will not want him to unexpectedly join others who are in the bathroom. If the child learns these actions as the first step in the routine, this will not be something you have to worry about happening.

Plan to use materials and strategies in your routine that will insure modesty, such as environmental or touch cues. Select a single location such as the bathroom (environmental cue) for disrobing. Don't allow the

child to start undressing in the den while you are finishing the last ten minutes of "ER" or in the hallway as you wrap up a phone call. Jumpstarting the bathing routine in these locations might save a few minutes, but you have taught that all of these locations are good places to disrobe. A shower wrap placed in the child's hand (a touch cue) before he or she pulls back the shower curtain and steps out into the room, cues him or her to cover up.

USE UNITS FOR SOME STUDENTS TO SUPPORT INSTRUCTION IN LEARNING THE RULES OF MODESTY

Units use practical experiences, which give children the concepts they are missing. They also tie this experience to language children need to discuss the information with others. Units are effective for students who can categorize and who already have the ability to represent information in an abstract manner (e.g. drawing pictures, signing, writing). An example of a basic unit on modesty is shown below.

Conclusion

Children with deaf-blindness and significant developmental delays do not understand society's complex rules about modesty. They may not understand concepts such as "private" and "alone." Additionally, their vision and hearing loss make it difficult for them to know whether others are present. Their lack of inhibitions related to modesty causes them to feel free to remove clothing or touch themselves inappropriately in public if they are uncomfortable. It is only through the use of systematic instruction and support that these individuals can successfully conform to a standard of modesty that will insure their success in community settings.

MODESTY UNIT

Concepts to learn:

1. Some places are private and some places are not private.

2. Changing clothes and adjusting clothes can only be done in a private place, and you must wait until you are in a private place to do these things.

3. Places in the community and at home have private areas.

Activities for instruction:

1. Have the student take pictures of his or her private places at home and make a book. Later add photographs of the private places out in the community.

2. Use repeated real-life opportunities to teach the concept and emphasize the sign for "private."

- Go to a grocery store for a few items and visit the restroom to fix a blouse that has come out.
- Go to a restaurant for a meal and make a trip to the restroom.
- Go shopping for clothes and change in the dressing room.

3. Cut out a magazine picture of a person in a towel. Use the photographs of places around the home, school, and community (hallways, parking lots, restroom at home) and have the student point to pictures of places where it is okay to be dressed in a towel.

4. Look for the teachable moment to emphasize the concept of privacy at school, home, and in the community. Seize those "embarrassing moments" as opportunities for instruction. Stay calm, talk about "private," and move them to a private area to address the problem.

Issue	Things To Try
Stripping in public places	◆ Determine why the behavior is occurring and develop a behavior plan to insure a consistent approach to resolving the problem: ➢ He/she is uncomfortable, ➢ His/her behavior is triggered by something in the environment, ➢ He/she is using his clothing to self-stimulate, or ➢ He/she is tearing his clothes because he is upset. ◆ Be calm and acknowledge the child's need to remove the clothing (e.g., "I know that shirt is hot" communicated by fanning the shirt away from his body), then redirect inappropriate behaviors by signing "wait" or "later" and move the child to a more appropriate location for removing his clothes. Avoid saying "no" and "stop." ◆ Try to distract him from the pursuit (e.g., fanning the child with a paper or taking him to the restroom where he can sponge his face and neck to cool down). ◆ Find more complicated clothing that is more difficult for the child to strip off before you can intervene and redirect (e.g., a shirt with buttons as opposed to a pullover). ◆ Redirect the behavior by signing "wait" and "private" and distract by providing something else for him/her to do.
Scratching private areas of the body in public	◆ Determine if there is a physical reason for the behavior such as a rash that might be caused by detergents, scratchy clothing, other environmental factors, or brought on by a medical condition such as a yeast infection. ◆ Redirect the behavior by signing "wait" and "private," and distract by providing something else for him/her to do.
Obvious and prolonged adjusting of undergarments in public	◆ Determine if there is a physical reason for the behavior, such as clothes that are poorly designed, are too tight or loose, or have tags or stitching that might be irritating. ◆ Determine if the child is using the clothing for self-stimulation, and provide more appropriate items for him to use in public settings such as keys on a key chain, a purse with a shoulder strap, or a wristband or bracelet. ◆ Acknowledge the child's concerns and redirect the behavior by signing "wait" and "private" and helping him/her move to a better location for adjusting the clothing.

Chapter 5

Appropriate Touch and Personal Boundaries

When a child is deaf-blind, one of his most important senses is touch. Through touch he is likely to find his way into the world, and the world will find a way to him. This is especially true if vision and hearing losses are extensive. However, even if the child has residual vision and hearing, touch is a primary way to confirm what he thinks he sees or hears. His communication system is likely to utilize touch in some form as well. For the deaf-blind child with significant developmental delays, that might mean touching object symbols to request an activity or giving a touch cue for help to complete a task. A child with more sophisticated language skills might read the signs with his hands in response to a question he has asked. The deaf-blind child usually experiences a caregiver's touch as he is assisted with dressing, toileting, and other activities. Orientation and mobility rely greatly on touch, both in terms of instruction and the use of a sighted guide. The child receives a great deal more touch than his typical peer. This is one reason why learning appropriate touch and personal boundaries is so important and often so difficult for the deaf-blind child. Like the other topics covered in this book, this one has unique issues associated with it for this group of children.

Issues About Touch and Personal Boundaries For The Child Who Is Deaf-Blind

RULES ABOUT TOUCH AND PERSONAL BOUNDARIES ARE DIFFICULT TO LEARN INCIDENTALLY

As a society we have strict and often complex rules about this subject. However, these rules vary from culture to culture, family to family, and individual to individual. Most of these rules are taught primarily through what typical people see and hear, and also through the way they experience touch.

Touch is a sensitive subject with the general public. Every culture has rather clear rules about touching. In most cultures, if you bump into someone by accident, you are expected to make an apology. To get someone's attention, you are expected to speak to the other person first.

If that fails, you might touch the person on the shoulder or perhaps the hand. You generally do not touch the person on the ear, the face, or the back of the leg. We learn most of these rules by incidentally observing the behavior of others and also through experience.

When people are deaf-blind and have developmental disabilities, most of these rules are not learned incidentally and may not be learned at all. If a deaf-blind individual breaks these rules, people can feel threatened. This is especially true if they perceive some sexual intent behind the violation.

A similar thing occurs with personal boundaries. In general, there are clearly recognized areas of personal space in a given society or culture. This personal space extends into invisible boundaries or circles around us. Sighted-hearing individuals move through a natural progression of expanding distances between others and themselves as they mature. When people converse they adjust the space between themselves and others, based on the topic being discussed and their relationship to the conversational partner. Crowded elevators clearly demonstrate personal boundaries. American culture typically dictates that people avoid eye contact, stand still with hands clasped or at their sides, and so forth. As people get off the elevator, the remaining riders might move further apart, make eye contact, smile or even chitchat. Deaf-blind individuals probably won't pick up on these rules incidentally. Failure to comply with these culturally "safe" distances may seem threatening to the general public and, depending on the situation and the age or sex of the offending individual, may take on sexual overtones.

DISTANCE IS "THE ENEMY" WHEN A CHILD IS DEAF-BLIND

Unfortunately, deaf-blind children are always at risk for innocently violating rules of personal space. The loss of vision and hearing, which occurs in this circumstance, means that distance is their enemy. Until people and things are very close or a deaf-blind child can touch them, persons or objects do not exist for all practical purposes. For example, a typical person might notice that the woman seated in front of him on the bus has a beautiful beaded hair clasp. Without making any real effort, he can admire it from the distance of about three feet. The deaf-blind child in the same situation may only be able to see bright colors against a dark background. The child wonders, "What is this pretty thing?" To be able to see it clearly he must move within two inches of the object. He is likely to reach out and touch the object. That helps to confirm what the object is. Which of the two behaviors is likely to cause the woman to feel threatened?

Children with deaf-blindness use touch, taste, and smell to understand their world in a way a sighted-hearing person never will. The culture of deaf-blindness endorses close personal space and frequent touching to confirm who and what has entered their world.

CHILDREN WITH DEAF-BLINDNESS EXPERIENCE TOUCH DIFFERENTLY

Deaf-blind children with developmental delays may perceive touch differently from their typical peers. Because of the limits in vision and hearing, more reliable information is often available to them through touch. Moving touch to the top of the sensory list for gathering and confirming information makes their approach to life completely different from their typical peers.

Deaf-blindness is something typical people can never truly experience, even under simulation. Children's sense of touch is greatly impacted by this condition and may result in the brain's developing differently from that of a sighted-hearing person. They are likely to use more areas of the brain to process touch. In her article, *Talking the Language of the Hands to the Hands*, Barbara Miles includes this quote from Dr. Harlan Lane (1999):

> *The ability of the human brain to adapt to changes in the environment, called cortical plasticity, is nothing short of astounding. Cortical plasticity involves much more than reinforcing brain areas that receive stimulation and shutting down areas that no longer receive stimulation from inoperative senses; it also involves, when some senses are depleted, compensatory changes in the nervous tissue serving other, remaining senses. The brain may sprout new connections in the tissue serving remaining senses, and it may also reallocate to those remaining senses brain areas that otherwise would have served the inoperative senses.*

Most often touch is thought of as something that is done with the hands even though sensations are experienced with all parts of the body. However, it is not unusual for deaf-blind children with significant developmental delays to use feet, tongues, legs, bottoms, and other body parts to explore the world. They may be much more comfortable and adept at using touch to gain information. By seeking and responding to tactual information differently, these children are more likely to break society's rules about appropriate touch and personal space.

CONFLICTING STANDARDS ABOUT PERSONAL SPACE AND TOUCH ARE USED IN INSTRUCTION

In chapter 4 we mentioned that one of the most effective ways to convey society's rules to a child with deaf-blindness and developmental disabilities is to model them in the interactions. However, society's rules about touch and personal boundaries may conflict with effective teaching strategies typically used with these children. As a result, the rules cannot be taught by consistently modeling them. This is especially true when working with children who have extremely limited vision and hearing, little or no formal language, and who lack the ability to imitate.

To show a deaf-blind child how to use a spoon to stir ingredients in a bowl, one needs to sit close to the child, perhaps bringing one's arm and hand under the child's hand while stirring. This strategy helps the child to detect and understand the action. For this particular child, using her arm to experience stirring may be the most efficient way to teach "stirring." This strategy very effectively teaches many activities to children in this group. However, if a deaf-blind child goes to a fast-food restaurant and innocently reaches for the arm of a stranger to "see" what that person is doing, the stranger is likely to be put off. The child has broken a rule about boundaries and touch. It is easy to understand why the child might have difficulty figuring out what is acceptable behavior when it comes to touch and personal boundaries.

CHILDREN WITH DEAF-BLINDNESS MAY GET THE WRONG MESSAGE ABOUT TOUCH AND PERSONAL BOUNDARIES

- *Touch and violating personal space can be a "weapon."*

A deaf-blind child may figure out that touch bothers some people. Touch that begins as a natural means of getting information can be shaped into touch that is used to terrorize. For example, there is a case in which a young woman had occasional aggressive outbursts that involved pushing, slapping and pulling another person's hair. She was beginning puberty and had just begun to develop breasts. In what appeared to be information seeking, she would calmly touch her breasts and then touch other people's chests, almost as if she were asking, "Do you have these things too?" When she learned that poking someone else's breasts consistently provoked a negative reaction, she began to incorporate this into her list of negative behaviors. She started jabbing and clutching women's breasts when she blew up. Although this behavior probably was not intended as a sexual act, it was perceived as being sexually aggressive. Suddenly the outbursts became much more serious to those individuals working with her.

Moving too close into someone's personal space can also be threatening and cause others to move away. Some children with deaf-blindness pick up on these responses and begin to use them in an aggressive manner.

- *Appropriate and innocent touch can be interpreted sexually.*

When some deaf-blind students begin to go through puberty, they may begin to respond sexually to the touch of a particular staff member or family member. This may occur even though the interactions involving touch are completely innocent and appropriate. While this is by no means common, it does occur. Of course, this is acutely uncomfortable for the recipient of the child's attention as well as challenging for the team and/or family to address.

Guidelines For Instruction and Intervention

HONOR THE CHILD'S LEARNING STYLE

Typical social rules about touch and personal boundaries may prevent these children from accessing information in the world around them. They have legitimate needs for instructional strategies that are tactually based and also take full advantage of residual vision and hearing. These individuals will always require touch and closeness to people and things in the environment. They need this in order to connect and be included with people and the events of life. They may also tune into tactual information to which typical people do not pay conscious attention, gathering important sensory information with their feet, tongues, legs, arms, and other body parts.

It is necessary that these children be accepted and also safe in society. However, the importance of this unique learning approach is well founded and should not be denied. To some degree the conflict between deaf-blind culture and the visual culture that drives society's rules will always be an issue. While society's perspective is important, the child's educational team needs to be sure that it's planning and instruction honor the child's learning style first.

MAKE SURE TO INCLUDE BASIC SOCIAL SKILLS GOALS IN EACH YEAR'S IEP

Each year your child's IEP should include goals focused on basic social skills since there is always some aspect of the child's social skills that can be improved. In the early years, this may mean focusing on appropriate greetings so the child learns that he or she does not hug and kiss everyone. It might focus on learning the specific body parts that may be touched without asking permission, on how close to stand to a person when ordering food in a restaurant, on what to do in a crowded elevator, and so forth. Assess the child's skills and determine which skills should have priority focus. Some critical skills related to appropriate touch and personal boundaries are learning greeting rituals, getting another person's attention, and gaining permission to move in close or to touch.

USE GREETING RITUALS

Remember that greetings go both ways. Your child needs a way to appropriately greet familiar and unfamiliar people. Just as importantly, other people need to learn how to introduce themselves to your child. This is truly one area where modeling can and should be used in instruction. Ask others to touch their hand to the child's and then guide the child's hand to a ring, a long braid of their hair, the side of a whiskered cheek, or anything distinctive that the person might choose. If

there is a consistent greeting ritual each time the child is approached, the child will be less likely to randomly search the person to determine who is present. It is also important to consistently pair name signs or specific symbols to people who have regular contact with the child. That way the child can identify them without needing to physically explore them each time.

TEACH APPROPRIATE WAYS TO GAIN ATTENTION AND ASK PERMISSION BEFORE TOUCHING

Show the child how to gain permission before touching or moving in more closely to see a person or their possessions. You can tell the child either "yes" or "no" or "wait" when he or she naturally moves in to interact with another person. This serves to let him know that sometimes he can touch and sometimes he cannot.

Teach the child to use a sign or signal such as "want see" or "want touch" to gain permission before touching or moving in too close. You should be prepared to facilitate the interaction by interpreting the child's request to the other person. Then you can signal the child when the person gives permission.

TEACH APPROPRIATE TOUCH THROUGH MODELING

At some point early on you should let your child or student know that touching some parts of another person's body is not allowed. This means teaching him not to touch, but also teaching him that he can refuse the touch of others. Using terms like "private" to signal these off-limit areas on his body and also on another person's body helps the child learn some of the rules of touch etiquette. Your rules may need to be very black and white. Especially since many of these children and young adults with developmental delays have rather intimate care giving needs that override the normal rules of touch.

It is always a good idea to build in the option for a child to resist another person's touch. Everyone needs to be able to say "no" to touch from time to time. When a child resists your touch, honor this resistance as the child's way of saying, "No, don't touch me there." If for some reason you must continue to touch him or her, at least back off and give him or her time to adjust to the idea of being touched. Give a signal to let the child know you need to touch again before attempting another interaction. Also try to think of ways to let the child have control of the touch as much as possible. You can do this by either having him do that step of the activity or at least do it together, using a hands-under-hands technique as suggested by Barbara Miles in her article *Talking the Language of the Hands to the Hands* (1999). There are times, especially in the area of medical management, when these strategies may not apply. Try to make aversive touch the exception, not the rule, for the child with deaf-blindness and developmental delays.

INCREASE BODY AWARENESS IN DEVELOPMENTALLY APPROPRIATE AND NEUTRAL WAYS

General body awareness is often an issue for the deaf-blind child who has significant developmental disabilities. Activities that focus on developing body awareness in developmentally appropriate and neutral ways is important. When the child is young the parent may try infant massage or Bonding and Relaxation Therapy (BART) techniques. Some of these techniques may even be appropriate as the child matures. Older individuals might benefit from regular sessions with a licensed massage therapist. Orientation training provided by an orientation and mobility specialist or with their support can be helpful as well. Incorporating body awareness through care giving routines such as bathing and grooming are natural opportunities for instruction. Remember to include names for the body parts, when you can, through whatever communication method is most appropriate for your child. Find natural opportunities to compare the child's hands to your hands, feet to feet, eyes to eyes, and so forth. Even simple imitative and turn-taking games (patty cake, clapping hands, stomping feet) can contribute to better body awareness.

FOCUS ON CONCEPT DEVELOPMENT

It is important to teach basic concepts and vocabulary to allow the child to ask for the additional sensory information he or she needs, such as "want touch," "want see," "want smell," and so forth. The child will need to know the names of various body parts and have some way to communicate about them either through referencing his or her own body, gesture, picture, sign, or so forth. Help the child learn the concepts related to distance such as "near" and "far." Teach verbs like "move" and "wait." "Wait" is an extremely important concept because it can buy you time. Time is what you need in many situations to help you assist the child in gaining the close access he needs to understand what is happening.

USE ROUTINES

Build "rules" related to touch and personal boundaries into daily routines. Almost any student can develop a rote understanding of the basics of touch and personal space in this way. For example, you can teach the child to shake hands in a greeting routine for teachers and students and teach hugging in the greeting routine for mom and dad. Another example might be teaching the child to go to the urinal that is not next to another person in a public restroom. Of course, you need to be aware that the rules you teach may work against you in some situations. Be prepared for the consequences. In the case of the restroom, it may take the young man longer to find a urinal that he feels he can use.

REQUIRE OTHERS TO USE APPROPRIATE TOUCH AND RESPECT PERSONAL BOUNDARIES

Expect others to show respect for your child in their interactions. Don't hesitate to intervene if others are not using appropriate sighted-guide techniques, not offering their hands to the child, or being too familiar with him or her. If people move in too closely or too quickly, you should feel comfortable asking them to do things in a different way. Too often, deaf-blind children learn that they are powerless to stop unwanted touch. They become passive and do not resist, even when touch is painful or abusive. How can the child learn what appropriate touch and personal boundaries are if he or she never experiences it?

BE PREPARED TO PROVIDE SUPPORT IN SOCIAL SITUATIONS

- *Be an "ambassador" and intervene to define personal boundaries and appropriate touch.*

Sometimes when you are providing intervention and support you will need to be like an ambassador. This means that you will need to explain the importance of touch and moving in closely to the person who may not understand the deaf-blind culture. If the child spots something that arouses curiosity and quickly goes for another person, you will need to intervene to reassure the person that the child or young adult is not about to attack them. Remember that the child's need to overcome distance can be misinterpreted. Explain that the child is only trying to see pretty earrings, touch the brightly colored fabric of a tie, or identify what is sticking out of a pocket. Assist the person in identifying him or herself or telling the child "no touch."

You may also be able to offer the other person some tips on how to interact appropriately with your child. There will always be those people who hug and kiss or who feel free to touch sensitive areas on the child's body without permission. It is often the adult who is too aggressive. Remember the dreaded aunt who likes to pinch cheeks?

- *Orient and prepare the child for what he is about to encounter.*

Give the deaf-blind child as much information as possible about the surroundings. Try to identify the people and things that are most likely to be of interest. Let the child know where others are in relation to where he or she is.

Deaf-blind children are often lost in space. They need an anchor, an object or a person in direct contact with them, in order to feel oriented. Be sure to use good sighted-guide techniques in social situations. This not only helps you control appropriate distance for the child it also lets the child have access to you for the support he or she needs to interact with

others. If you must leave your child for a moment, don't leave him alone without explanation. Make sure your child knows that you have left and will return. Also be sure he has something with which to connect such as a chair or a wall. If you don't provide this support, the child will probably search for it on his own and perhaps make a bad choice. Using the sign for "wait" can be a good cue to let the child know that being out of contact with you is only temporary. Parents and teachers should begin early to teach the child this concept.

- *Avoid trigger situations.*

Some children with deaf-blindness, like many non-disabled people, have objects that they just cannot resist. A child who is absolutely fascinated by red aprons and always looking for a way to get a closer look shouldn't be set up. Be aware that the restaurant where all the waiters wear red aprons is trouble waiting to happen. Switch restaurants, or if you must go to that particular place, leave your child at home with the babysitter. A child who has learned some rules of touch and personal space might be able to control herself for a time if you discuss the behavior. Acknowledge that you see a person with a red apron nearby and remind her that she must "ask first" before she touches it. Be prepared, however, to have the same discussion many times during the course of the dinner. If you know something is going to be a problem, make every effort to avoid it. If you cannot avoid it, be prepared to address it repeatedly.

- *Redirect.*

When you find yourself in the role of the ambassador, you can evaluate the situation and determine both the child and the other person's comfort level. You may choose to divert the child's interest in an object or a person by redirecting him to another object or to one that is on a less sensitive area of the person's body. Touching a necklace might make a person uncomfortable, but that person might be able to let the child examine a bracelet at close range. You may even need to redirect the child to another person who may be more comfortable with the interaction. For example, parents are sometimes unsure of an older child's interacting with a toddler, but they are content to have him or her interact with a child of similar age or an adult.

The very nature of the child's disability causes him or her break the normal rules of personal boundaries. While this can put people off who do not understand why the child is moving in so closely, most people are willing to drop their rules if they understand the child's needs. Again, teaching the child to ask before he or she moves in too closely can help at times. Just be aware that this is asking a lot of the child. It is like expecting you to ask permission before you look at or listen to what is happening around you. You can do it some of the time, but it is not very effective on a regular basis.

ADDRESS ISSUES RELATED TO PERSEVERATIVE TOUCHING

Occasionally a child with sensory impairments and developmental delays will become fixated on or even obsessive about a particular object, person, or activity. He may constantly talk about, seek out, or try to acquire the object of his fixation or obsession. We call this perseveration. Sometimes a perseverative behavior may cause the child to inappropriately touch or violate personal boundaries. In one case a young man was fascinated with belts. He would sometimes wear more than one belt at a time, and he loved to look at them in fashion magazines in his spare time. He would search the family closets, take the belts he found, and then hide them. Of course, he liked to touch belts with his hands, but he also liked to touch them with his tongue. He would visually examine them very closely. It didn't matter who was wearing the belt or where they were when he spotted them. Needless to say, his obsession with belts created many problems for him and his caregivers. Behavior like this is not about misunderstanding appropriate touch. It is perseveration, and it needs to be addressed in a formal behavior plan.

DEVELOP A BEHAVIOR PLAN IF NECESSARY

For some children, inappropriate touching and violation of personal boundaries have become ingrained behaviors. They may even be perseverative behaviors that may sometimes evolve into actual aggression in which the child uses this behavior as a weapon. Because of society's rules about appropriate touching and personal boundaries, these behaviors may be perceived as sexually threatening. This may be true even when they are not intended that way. Your team may not feel equipped to address behaviors that take on these perceived sexual overtones. While it is important not to minimize the sexual aspect of an incident, it is helpful to remember that the steps to approaching these behaviors are the same as they would be for any other behavior.

Habitual, perseverative, and aggressive behavior should be addressed through the development of a behavior plan. This plan should have strategies that are both proactive (heading the behavior off before it occurs) and reactive (responding to the behavior once it has occurred). The first step is to identify the triggers for this behavior so that family and staff can be alert to a possible incident and be prepared to intervene. Clearly identify the appropriate behavior that you want to see the child exhibit and the consequences for the unacceptable behavior. Strategize ways to reinforce the desirable target behavior.

You should also have a plan for intervening calmly to address the behavior when it occurs in order to reduce its impact. Often the best approach is to divert or redirect the child. Don't forget that the more anxious or excited you become, the more power you give to the problem behavior. Of course, consistency between home and school in addressing problem behaviors is critical.

The behavior plan for the young man who perseverated on belts used both proactive and reactive strategies. His team wanted him to be able to control his compulsion to touch belts, especially if the belts were on strangers. A belt was included in his daily calendar to signify a set time when belts could be discussed and enjoyed. Staff provided him with other information about the belts during the calendar discussion. They pointed out how belts have different colors, textures, and sizes; and so forth. They showed him that belts could be given as presents to others. Since this student understood the concept of "rules," they also made a book of rules about belts. In every situation the staff and family was aware that belts could present problems for the child and for them. They developed a consistent and calm approach to redirect and contain the behavior by telling him "no private" before he successfully touched someone's belt. They reminded him that he needed to "wait for belt time" when he could play with the belts in his collection. Over time they were able to gain better control of his behavior.

Developing such strategies and using them consistently generally help to reduce the number of incidents, but they will not necessarily eliminate the behavior. Some behaviors are beyond the child's ability to control, and being alert to those situations and being prepared to intervene are all that can be done to help.

CONSIDER MAKING CHANGES IN ROUTINES OR CAREGIVERS IN SOME SITUATIONS

Occasionally children beginning puberty may start responding sexually to touch that is not meant sexually. They may never have responded in that way before, and when it happens caregivers and staff can become very distressed. They may feel threatened by the child, or they may think that others will accuse them of behaving improperly with the child. When this does occur, it is important to take time to figure out who or what is triggering the response. Is it something in a routine or is it a response to the person? In some cases the simplest solution is to change staffing patterns for a particular activity. Redesigning a routine to reduce the nearness of the staff person and to use different physical prompts may also work.

SOME CHILDREN BENEFIT FROM UNITS RELATED TO APPROPRIATE TOUCH AND PERSONAL BOUNDARIES

For the student who can categorize and who already has the ability to represent information in an abstract manner (drawing pictures, writing, signing, etc.), the use of instructional units is important. Below is a sample of a unit on appropriate touch.

Conclusion

Learning appropriate touch and personal boundaries is one of the most difficult tasks faced by the child with developmental delays who is also deaf-blind. The rules don't make sense in his or her world where distance is the enemy. To further complicate the issue, the rules really only work for approaching others, not for the way in which they approach the child. His or her need to get close and touch in order to make sense of the world must be recognized at all times. It is not unreasonable to expect the child to learn some of the etiquette of appropriate touch and personal boundaries. Families and caregivers must first be prepared to provide the necessary intervention and instruction. Most importantly, they must show greater respect in how they touch the deaf-blind child.

Sample Unit on Appropriate Touch and Personal Boundaries

Concepts to learn:

1. Names of basic body parts including the breasts and genitals, as well as "near," "far," and "move."

2. Touching someone on the hand, arm, or shoulder to get his or her attention.

3. Asking permission before touching someone on a place other than the hand, arm, or shoulder.

4. Some places on the body are only touched in private and with permission.

5. Appropriate personal boundaries mean being at least an arm's length away most of the time.

Activities for instruction:

1. Role-play getting another person's attention.

2. Practice getting people's attention throughout the day at the bus stop, in the classroom, the cafeteria, on the playground, at home, and in the community.

3. Use anatomically correct figures and point to and name the body parts, including the breasts and genitals.

4. Name the places on the body that can only be touched in private.

5. Provide art or sandbox activities in which the child, the staff, and peers explore materials together with their hands using simultaneous touch and hand-over-hand or hand-under-hand techniques.

6. Teach the concepts "near," "far," and "move" by acting out moving from near to far, placing objects at near and far distances, and discussing locations of favorite objects and people as being near or far.

7. Discuss and role-play keeping an arm's length of distance from a peer as you stand in line, place chairs in the morning circle, walk to the playground, etc.

8. Cut out pictures or demonstrate activities for which it is permissible to get close to another (hugging mom and dad, wrestling with brother, riding with a friend on a bicycle, holding a baby, etc.).

9. Use repeated real-life situations to teach and reinforce concepts about appropriate touch and personal boundaries.

- Have the child use hand-under-hand or hand-over-hand techniques to explore new objects or to locate a person's hand.
- Practice greeting people using name signs and an identifying touch.
- Practice asking permission to touch objects or other people.
- Practice keeping an appropriate distance from others when interacting.

10. Look for the teachable moment to emphasize appropriate touch at school, home, and in the community. Seize those "embarrassing moments" as opportunities for instruction. Stay calm, ask the child to wait, talk about "private," "ask first," "near," "move," etc. Assist the child to have appropriate interactions with individuals whenever it is possible.

Troubleshooting Issues with Touch and Personal Boundaries

Issue	Things to Try
Violating personal boundaries and touching for more information	◆ Use teachable moments to calmly model the right way to get information using good social skills. ◆ Provide adequate support in social situations: be an ambassador and orient and redirect the child. ◆ Provide more information to the child in a neutral manner through the use of units.
Aggressive touching	◆ Develop a behavior plan that is both proactive and reactive.
Inappropriate hugging or kissing	◆ Teach appropriate greeting rituals. ◆ If the student understands rules, make lists of those people he may and may not hug or kiss. ◆ Use appropriate greetings and displays of affection with the child.
Perseveration that results in inappropriate touch	◆ Develop a behavior plan. ◆ Schedule times during the day for the behavior. ◆ If the student understands rules, develop rules about the particular behavior. ◆ Avoid and plan for trigger situations.

Responding sexually to touch that was not meant sexually	◆ Determine who or what is triggering the response. ◆ Consider switching staff/caregivers during this particular activity. ◆ Reevaluate the amount of touch needed to assist the child and reduce touch or increase distance if possible.

Reference Miles, B. (1999). Talking the Language of the Hands to the Hands. (Fact Sheet). Monmouth, OR: DB-LINK, The National Information Clearinghouse On Children Who Are Deaf-Blind. Available at http://www.tr.wou.edu/dblink

Chapter 6

Menstruation

When any young woman begins to experience the physical and emotional changes that puberty brings, parents feel unprepared. Helping their child learn to take care of her physical needs and, at the same time, coping with emotions and behaviors that are associated with menses are challenges. Parents of children with deaf-blindness and significant developmental delays do not escape this important milestone in their daughter's life, and they too feel unprepared. It is our hope that by learning some strategies for providing instruction and support, this experience will be easier for everyone involved. Parents and caregivers should not have to dread this coming of age for the young deaf-blind woman. They should be able to feel positively about this very wonderful and normal aspect of growing up.

Issues For The Young Woman Who Is Deaf-Blind Related To Menses

THE YOUNG WOMAN MAY NOT BE FAMILIAR WITH WHAT ARE ACCEPTABLE "PUBLIC" BEHAVIORS

Because the young deaf-blind woman who has developmental disabilities usually cannot see or hear when others are around, she may lack a sense of which behaviors are appropriate for public settings. Even if she is aware that some behaviors are "private" she may lack strategies for determining that she has found a private space where she cannot be seen or heard. Typically she is used to having caregivers with her when she changes, goes to the restroom, bathes, and so forth. Furthermore, her caregivers may not always assure her privacy before carrying out intimate caregiving routines.

THE YOUNG WOMAN MAY LACK SOME OF THE BASIC CONCEPTS AND VOCABULARY ASSOCIATED WITH MENSES

Many children with deaf-blindness and significant developmental delays lack basic concepts and vocabulary to enable them to discuss what is happening to their bodies or to indicate when they are in physical discomfort. Many words and concepts like "woman," "baby," "egg," "pe-

riod," "hurt," "blood," "vagina," "private," and "breast" may not have been learned. Some young women may be incapable of learning many of these concepts, and/or parents and teachers may not know how to teach them. Caregivers may not know which signals, signs, or cues to use for words, especially when children need to receive information tactually. Even using an object cue for some thing like sanitary pad may seem awkward to some parents and teachers. Many teenaged deaf-blind girls don't have a level of communication skills that allows for instruction using traditional methods such as films, books, and discussion.

SHE MAY NOT LEARN INCIDENTALLY THROUGH INFORMAL MODELING OR INSTRUCTION

Typical teenagers become aware of menstruation long before their first period through commercials on television, discussions with their peers, observing their mother or older sister, and so forth. A young woman with sensory loss and developmental disabilities generally misses out on this informal or incidental learning. She may not have seen a sanitary pad, watched a commercial for Midol or Kotex, or have any knowledge of the changes her own body is undergoing. She is certainly unlikely to understand the reproductive process that is associated with her menses. Like too many other things in her life, this just happens to her without explanation or preparation.

SHE MAY REQUIRE MORE OPPORTUNITIES TO PRACTICE SKILLS WHEN HER PERIOD ONLY OCCURS ONCE A MONTH

Generally these children take more time to learn new skills. A young woman's period will generally last about three to five days and occurs about once each month. If she begins to learn the steps of a different toileting routine on the first day of her period, she may not master the skills by the time her period has ends. By the time her next period comes around, she may have forgotten the skills she had practiced before. She basically starts all over again to learn the skills she had practiced during her last period. Instructing her will most likely take longer, even if she is only partially participating in this hygiene activity.

SHE MAY BE CONFUSED AND UPSET BY THE CHANGE IN HER TOILETING ROUTINE

Some young deaf-blind women may not be independent in their toileting routine. They may not be prepared for the changes that occur as their caregivers take additional steps to change a soiled pad. Even if a young woman is independent in her toileting needs, she may resist adding steps to a routine that has stayed the same for a long period of time. The new smells and new textures may also confuse her, not to mention the physical discomfort that she may feel. She may think she needs to go to the restroom or feel she has had an accident. All of these things can be confusing and upsetting.

PHYSICAL AND HORMONAL CHANGES THAT ARE NORMAL DURING PUBERTY MAY RESULT IN BEHAVIORS THAT ARE DIFFICULT TO ADDRESS

As any mother or father of a pubescent daughter knows, hormones change their sweet little girl into a moody and difficult creature at times. Fits of anger, depression, crying, and sensitive feelings are all common to the teenage female, especially around her period. Some girls must cope with growing breasts that are periodically sore, cramps, bloating, and signs of PMS. Most parents will tell you that their daughters' behavioral changes can be challenging during this time. A young woman with deaf-blindness and significant developmental delays is no different in this respect. However, her sense of appropriate behavior is not usually as well developed as that of her typical peers. She may be more likely to act out aggressively when she is in pain or to become inconsolably weepy and fragile. She may be frightened by what she is feeling.

BEHAVIOR PROBLEMS MAY OCCUR IF THE YOUNG WOMAN FEELS SHE HAS DONE SOMETHING WRONG

Assisting another person with her period is a very intimate task. Although it is somewhat like a basic toileting routine, it has different connotations. It is a coming of age for a girl. It signals her coming sexuality in a way that makes people respond to her differently. Frequently caregivers can be abrupt with a young woman when helping her with her menstrual needs. Consider the situation of a caregiver hurriedly changing a sanitary napkin. The young woman reaches down to touch the pad. Her hand is pushed away abruptly several times. The caregiver's behavior upsets her, leading to a combative situation about the pad. Several exchanges of this nature through the day could set up a pattern of behavior that may be very difficult to change, such as pulling at the pad, smearing menses, or other inappropriate behaviors.

Guidelines For Instruction and Intervention

MEET WITH YOUR SCHOOL TEAM AND DEVELOP A MANAGEMENT PLAN

Collaborate with your educational team to develop a plan for menstruation management before beginning instruction. Parental input can help your team plan instructional strategies. Parents need to feel comfortable with how instruction will be provided at school. They need to be reassured that their daughter will receive support and understanding as she goes through what may be a trying experience. Educational staff members need reassurance too. They may also bring expertise to the process.

Don't be surprised if individuals on your team feel it is too early to plan for this event or unnecessary to discuss the issue. Both parents and educational staff have been known to think of the young deaf-blind woman

as an eternal child. Although there are some etiologies that may impact sexual development, generally this is an area where a girl with deaf-blindness is most like her peers.

Teach your daughter about periods long before you anticipate the first one occurring. Learning words and concepts may take time, so begin early to introduce them to her. Even when she is just a toddler you can teach words and concepts such as "clean," "dirty," "wet," "restroom," "breasts," "vagina," "vulva," "throw away," "private," "wait," and so forth. This is also true of skills related to independent toileting and dressing. Begin to include goals to work on these concepts and skills at the earliest possible age. You know this is coming sometime in her future, so don't get caught trying to provide instruction at the last minute.

Develop a management plan that includes the following components:

- a list of concepts/vocabulary (in the form of signals, symbols, signs, or pictures, etc.),
- an inventory of supplies that will need to be available at school and at home,
- a routine script for changing the pad,
- a protocol for providing medication if it is necessary,
- appropriate modifications of the instructional day if she is having problems,
- a protocol for communication between home and school about any concerns, successes, etc.

A sample of such a plan is shown below:

Menstruation Management Plan

Student's name: Linda

Concepts / vocabulary targeted: private, period, pad, blood, red, white, vagina/vulva, breasts, head, stomach, hurt, tape, clean, dirty, change, restroom, urine, feces, trash, doctor, exam, in, on, throw away, bag, toilet paper, medicine.

Supplies for home and school: sanitary pads, latex gloves, small zipper-lock bags, zipper pouch to carry pads in, Midol, extra underwear, object symbols for calendar boxes at home and school, and notebook.

Routine steps: *At home and school include the object symbol for period (zipper pouch with pads) in her calendar at scheduled toileting times.*

1. Linda finds the object symbol in her calendar box and gives the sign for period.
2. Intervener coactively signs/signals, "change pad," Linda carries the zipper pouch containing her supplies, and they travel together to the restroom.

3. Linda gives the pouch to her intervener, enters the restroom, and is assisted to close the stall or bathroom door.

4. a. (WHEN NO PAD IS ON) Linda pulls down her underwear, uses the restroom, and wipes with toilet paper as in her normal toileting routine.

   b. (WHEN PAD IS SOILED) Linda pulls down her underwear and sits on the toilet and the intervener coactively signs "dirty pad off" and removes the soiled pad. The intervener has Linda hold the zip-lock bag while she folds and places the pad inside. Intervener signs/signals "in trash" and Linda closes and throws the bag in the trash.

5. The intervener signals Linda by coactively signing "clean pad" and shows her the clean sanitary pad. The intervener comments "blood no dry" and points out the clean surface.

6. Linda examines the pad tactually and when she has finished, the intervener coactively signs/signals "tape off" and assists Linda in removing the tape and "in trash" as she assists Linda in throwing the tape guard in the trash receptacle.

7. The intervener coactively signs/signals "pad on panties" and helps her secure the pad.

8. The intervener coactively signs/signals "panties up," and Linda completes additional dressing steps independently. The intervener signs "change pad finished" and directs Linda to wash her hands as in her normal toileting routine.

9. Linda and the intervener travel to the room and replace the pouch before discussing the activity at her calendar.

Medication: If Linda appears to be in pain or signals by signing "hurt stomach," "head," "breast," or "medicine," the nurse can give her Midol pills during the school day. If the pain persists, the school nurse will contact Linda's mother to come take her home.

Reduced activity: Linda may rest on her mat whenever she chooses after attempting the scheduled activity. PE activities should be restricted to swinging, yoga, or a walk.

PROVIDE INSTRUCTION PRIOR TO YOUR DAUGHTER'S FIRST PERIOD

- *Let her wear the sanitary pad for specific lengths of time on a daily basis.*

By starting in advance of the menses, parents and staff will have the opportunity to prepare the young woman in a positive manner. Let her become familiar with the pad by wearing one for specific lengths of time on a daily basis. This will allow her to learn about the pad without experiencing the added physical or emotional discomfort of being in her period for the first time. The unusual sensation of a pad may be unacceptable to her, and she may react by pulling it off repeatedly when it is first introduced. Should this happen, it will be less stressful for everyone if dealing with a dry pad in a private place.

- *Try out different pads and select one that is most comfortable for your daughter.*

Take time to let your daughter try out different pads and select the one that is most comfortable for her. Start with the smallest size available, such as panty liners, and build gradually to the thicker pads. It is better to change pads more frequently and use a thinner more comfortable variety than to engage in a power struggle with a young woman who is intent on rejecting an uncomfortable pad.

- *Practice changing the pad regularly.*

Give your daughter time to practice the new skills involved in changing a pad (taking the paper strip off the back of the pad, attaching the pad to undergarments, disposing of the pad after it has been used, etc.). If you present these new skills only while your daughter is menstruating, she may not have enough opportunities in those few days each month to learn independence in the routine.

STAY MATTER-OF-FACT WHEN TEACHING MENSTRUATION MANAGEMENT

It is important to be positive, organized, and relaxed. Address menstruation management as if you were teaching toothbrushing and handwashing. Be careful not to teach negative behaviors with this particular hygiene activity. If changing pads offends you or if you view training your child as a waste of time, your daughter may receive a negative message about the activity. People in our culture may be deeply offended or frightened by a young woman who pulls off her sanitary napkin in a public place. Once learned, this kind of behavior is very difficult to redirect, so it is better to avoid its development in the first place. Even if inappropriate behaviors do not develop, treating a young woman abruptly while changing pads can make her feel that she has done something wrong. This is not fair to her and certainly not beneficial in developing a good self-concept about her body.

MAKE SURE SHE UNDERSTANDS THAT THE HYGIENE ROUTINE MUST OCCUR IN A PRIVATE PLACE

It is important to make sure that this activity always occurs in a private place and that the young woman understands this. Include a step in the routine to close doors. If she is still in diapers, make sure her privacy is respected. Have an appropriate changing area in the school. Require staffing patterns that provide a female attendant for this activity. Help the young woman to understand as much as possible that not just anyone may assist her. Clearly identify and limit the number of people who help her with this activity. If she starts to pull on the pad in other places, tell her "wait" and take her to the area where this activity should occur.

Even if she has just finished changing the pad, she needs to make the association that the pad is not removed except in designated changing areas.

TAKE STEPS TO REDUCE THE YOUNG WOMAN'S CONFUSION

Sometimes young deaf-blind women who also have developmental disabilities confuse their period with a toileting accident and become distressed. They may keep insisting they need to use the restroom. If the young woman feels the need to go to the bathroom more often, let her. You can use this opportunity to practice changing the pad. Let your reassuring manner tell her that she is doing the right thing. Praise her success and be proud of her independence.

Another area of confusion is related to pad disposal. Your daughter or student may want to flush it down the commode like toilet paper. Take special care to guide her (hand-over-hand if necessary) to dispose of the pad in the proper container near the commode. You may want to consider purchasing a small trash receptacle with a lid that is used exclusively for this purpose. Schools may choose to purchase the type of wall containers that are found in most public restrooms to help make the environment as typical of other public restrooms as possible. If she is not good at handling the soiled pad, provide a small plastic or paper bag for her to place it in (or for you to place it in) and then have her dispose of it in the container.

HANDLE MENSTRUAL PROBLEMS IN A PROACTIVE MANNER

Before your daughter has her first period, make an appointment to talk with your family doctor or nurse about premenstrual stress syndrome. As she gets a little older (about eighteen or nineteen) you should also discuss the need for a gynecological examination and start planning a way to assist your daughter in going through that examination. Do not assume that this examination is not really necessary. Women with deaf-blindness and developmental delays are subject to the same gynecological health as their nondisabled peers.

Keep a record of your daughter's periods to detect irregularities that may warrant medical attention. There may be predictable health risks associated with some syndromes or based on family history. This is good information to document and share. Also, following a round of antibiotics, watch for yeast infections that can cause discomfort, especially during her period.

The young woman's doctor may suggest giving her aspirin or a non-aspirin product for the first several days of her period. This can help make her more comfortable and may head off problems if her communication level prevents her from letting you know she has cramps.

DON'T EXPECT THE DAY TO GO AS USUAL

You may need to change the young woman's daily routine, especially at school. For example, if she usually likes to jump on a trampoline but keeps getting off during the first day of her period, give her other activity choices that are not as physically taxing.

Parents and teachers should expect that if a daughter or student is having her period, less will get done and schedules may have to be adjusted. It is almost impossible to maintain the number of activities in a typical day and still find time to teach the critical skills of menstruation management. As a caregiver, if you are too rushed, you will do most of the work yourself. When that happens, an opportunity to gain independence has been lost.

USE THE YOUNG WOMAN'S CALENDAR SYSTEM TO HELP HER ANTICIPATE MENSTRUAL MANAGEMENT ACTIVITIES

It helps to actually schedule this hygiene activity into the day. For example, put a pad in a small makeup bag, place it in your child's room or student's calendar box, and have her be responsible for carrying it to and from the bathroom. If she uses a weekly or multi-weekly calendar, schedule her periods on the calendar. Help her to anticipate her period by going to buy pads at a grocery store. Talk about her upcoming period with her as you review the calendar together. If she does not use this type of calendar, use the bag with the pad as a topic of conversation during her usual hygiene activities.

Make thing easier for yourself by always having extra pads, latex gloves, and a change of clothing on hand. You can help her pack these items into a backpack for outings or trips to and from school. The better prepared she is for her period, the easier it will be on her and you.

WHEN PROBLEMS OCCUR, TRY TO SEE THE ACTIVITY FROM THE YOUNG WOMAN'S PERSPECTIVE

If your daughter or student refuses to participate in the menstruation management activity, consider whether this is a pattern of behavior she exhibits in other situations. Don't put any more emphasis on this activity than you would other types of hygiene activities. If you do, you may set yourself up for a power struggle.

You might understand the cause for her unwillingness to participate by noting other activities she does not like. What are the similarities between those activities and the menstruation management routine? For example, does she dislike touching tape or other adhesive surfaces? Does she have a preference for certain textures against her skin? Does she show aversion to handling things that are damp?

Consider the activity's design. Is she experiencing the same sequence of events every time she changes pads? Check with other caregivers who help her with this activity. If they are having the same problems, you might help each other to find solutions. If they are not having problems, you may want to make sure you are using their approach.

MAKE SURE YOUR TEAM COMMUNICATES REGULARLY WITH EACH OTHER ABOUT PROGRESS AND PROBLEMS WITH MENSTRUAL MANAGEMENT

Probably the most important thing you can do to help your daughter become independent is to communicate with all of those individuals who will assist her in this activity throughout her day. If a particular type of pad is used at school because she finds it the most comfortable, be sure to know that so it can also be used at home. If your doctor recommends a premenstrual medication, talk to the teacher and school nurse about the policy for administering it. Don't assume that a note from you will guarantee that the medication will be given in a school setting. Send a note or write a message to the teacher in her communication notebook so she will be aware of behaviors that may result from this impending event.

Work together to build strategies for supporting the young woman with deaf-blindness and significant developmental delays during this time. Most importantly, make sure everyone is committed to making this experience a valuable learning opportunity for her. Do not be shy about asking for help. Someone has probably experienced this many times before, as a parent or teacher, while it may be your first time.

Troubleshooting Problems

If you are reading this for the first time after your daughter or student has already started having her period, you may be thinking, "If I only knew this five years ago." You may even be having some real problems managing her period and behaviors resulting from how you are dealing with her period. What can you do to turn things around now?

TAKE TIME TO DO SOME DETECTIVE WORK

The first step is to do some detective work with the other caregivers in the young woman's life. Write down clear statements about all of the problems you are experiencing. Discuss what may be causing them. Do the problems stem from medical concerns, lack of concepts or vocabulary, too little or too much assistance being provided in the routine, or from differences in home and school routines? Is there something aversive about the activity such as an unusual smell, a rough approach from the caregiver, not enough support? Does this happen at home, at school, or both places? What is the difference if it does not occur in both places? It is important to take time to collect information about where things are breaking down. You cannot fix something until you are sure what is going wrong.

WORK AS A TEAM TO FIND AND TRY OUT POSSIBLE SOLUTIONS

Once you have determined what the problem is, there are probably two or three different solutions. Your school may be able to provide some additional expertise. Even though the teacher or aide may not have a lot of experience with deaf-blindness, they will likely know someone who is very skilled in addressing hygiene training. You may also want to visit with other parents who are a little further down the road than you, to see if they have dealt with similar problems. Most importantly, you and your school staff need to work as a team to identify the problem and to support each other in finding solutions.

Every child and every situation is unique and will have its own solution. However, there are some tips that may help you included in the following chart.

Troubleshooting Issues with Menstruation Management

Issue	Things to Try
Pulling off sanitary pad	◆ Try other pads. ◆ Redirect her to the restroom and allow her to change pad. ◆ Consider other type of pad.
Playing with soiled pad	◆ Allow her time to examine clean pad. ◆ Provide more assistance removing and disposing of pad.
Smearing menses	◆ Provide more opportunities to go to the toilet and supervise closely. ◆ Assist her with removing the pad and disposing of it.
Constantly requesting the restroom	◆ Let her go as often as she needs and practice changing pads. ◆ Work on concepts "wet," "dry," "blood," "feces," "urine," "red." ◆ Praise her efforts to keep the pad changed.
Flushing stained underwear or soiled pad	◆ Provide a bag for carrying home soiled underwear or for storing it until she can help wash them out. ◆ Provide a trash receptacle next to the toilet and guide her to throw soiled pad in it. ◆ Praise her efforts to appropriately dispose items.

Excessive physical discomfort	◆ See doctor about health issues such as yeast infection, endometriosis, constipation, etc. ◆ Request prescription or over-the-counter PMS medication. ◆ Increase or start a regular exercise program that works on relaxation such as yoga, swimming, or walking. ◆ Allow frequent breaks and provide a place for her to lie down. ◆ Use relaxation techniques such as deep breathing, massage, heating pads, etc.
Excessive emotions	◆ Reduce demands. ◆ Practice relaxation techniques such as deep breathing, massage, resting. ◆ Increase or start a regular exercise program that works on relaxation such as yoga, swimming, or walking.

Conclusion

Menstruation is a normal part of growing up for a young woman with deaf-blindness and significant developmental delays. It should be celebrated, not dreaded. You can help to prepare your daughter for this rite of passage beginning from a very early age. Start by working on concept development, communication skills, independent living skills, and social skills. There is a lot that can be learned before you actually deal with her first period. If you and your educational team do the work a little each year, chances are you will find that you can help a young deaf-blind woman to manage her period.

Chapter 7

Masturbation

This is perhaps one of the most controversial topics related to sexuality education. Because this topic provokes strong feelings tied to both cultural and religious values and beliefs, it is a very difficult topic for most parents and educators to address.

A range of beliefs and values about masturbation exists among parents and educators. Most people's beliefs and values can be captured in one of the four statements below:

- Masturbation is a normal healthy behavior that occurs in all human beings as they develop sexually, and it should not be stopped.
- Masturbation is an acceptable behavior if it is done in private.
- Masturbation is a shameful behavior that, if practiced, must be kept private.
- Masturbation is a sinful or shameful behavior that must be stopped.

It is unlikely that these varied perspectives will find a common moral ground. However, no matter what beliefs or values exist about masturbation, there is generally agreement about society's rules related to it.

- Masturbation is unacceptable in public places.
- Masturbating in public is a deviant behavior that violates certain laws.
- A person who masturbates in public is unwelcome and avoided.
- A person who masturbates in public invites advances from sexual predators.

Regardless of personal beliefs and because standards exist in society, it is in the best interest of children to address masturbation as a part of sexuality education.

Issues About Masturbation In Children Who Are Deaf-Blind

THE DEAF-BLIND CHILD'S ISSUES

- *The child experiences masturbation as just another type of bodily sensation.*

The world of the child who is deaf-blind with significant developmental delays is very different from that of a typical child. Depending on the degree of the vision and hearing loss, he or she is likely to be extremely focused within the body. Life is a series of sensations largely bound in smell, touch, and taste. The entire body is the sense organ used to explore the world. The deaf-blind child often does not have the social inhibitions that a typical peer has about seeking out a particular sensation. To the deaf-blind child, masturbation more than likely is just another interesting and enjoyable bodily sensation.

- *The child does not incidentally learn society's rules about public and private behaviors.*

As has been noted again and again in this book, incidentally learning about what is or is not an acceptable public behavior is almost impossible if one is deaf-blind and has developmental disabilities. Most of society's rules related to masturbation were never formally taught; they were learned incidentally.

- *The child may not be capable of understanding others' beliefs and values about masturbation.*

The child may also lack basic concepts that would allow him or her to understand the values and beliefs of his family or others. The child's language, communication and experience are likely to be limited. The child may learn to control an impulse to masturbate for a time, but he or she may never really understand the moral values that guide others to participate in or refrain from this behavior.

- *A child may utilize masturbation strategies or tools that are harmful or dangerous.*

A child with deaf-blindness and developmental delays is sometimes very creative with the strategies and tools they use in masturbation. Occasionally a child or young adult may select devices that are dangerous and his or her health and safety may be at risk because of this behavior. An example of this is the young man who tried to use a hair dryer as a masturbation tool.

- *Some individuals may utilize a more passive and unaware peer in their masturbation.*

Occasionally, an individual with sensory and cognitive disabilities will seek out another more passive peer to utilize as a tool for masturbation. He or she is not seeking out a relationship with the individual, nor is he

or she particularly sexually attracted to that individual. Rather, he treats the individual much like an object. The more passive individual may actually be a willing but unaware partner in this act of coupling. However, the notion of a romantic encounter is not part of this interaction. The partner may be of a different sex or of the same sex. The deciding factor often is based more on proximity and passivity than on anything else.

When one partner, in his attempt to masturbate, couples with an unwilling partner or someone who resists or is unable to give consent , it can be considered sexual abuse. Would the aggressor who was deaf-blind with developmental delays be successfully convicted of rape or abuse if these couplings occurred? Possibly not. Could the coupling result in unwanted pregnancy, the spread of sexually transmitted disease, injury, or trauma? It could happen. Might the deaf-blind individual be subjected to institutionalization or other extreme consequences as a result of this behavior? It has happened. Could a family or program be held liable for the individual's actions? It is certainly possible. But the bottom line is that no matter what the legal or health consequences are, parents do not want to see their child hurt another individual intentionally or unintentionally. Unnecessary

PARENT AND STAFF ISSUES

- *Masturbation may seem easier to ignore than to address.*

There are a number of reasons why family and professionals may choose to ignore a child who is masturbating. Both parents and professionals are often too embarrassed to discuss it. Sometimes this event heralds the arrival of a whole new set of issues related to adulthood for the child's parents. They would rather not face the fact that their little boy or girl is becoming an adult. Another reason that parents and professionals choose to ignore masturbation is fear about why the behavior is occurring. They may be aware that one of the indicators for sexual abuse in a typical child is the exhibition of sexually inappropriate behaviors. Perhaps the main reason why parents and professionals ignore masturbation is that they do not know what to do.

- *Family members and/or staff may not agree that the behavior is occurring.*

Many children with deaf-blindness and significant developmental delays are fixated on bodily sensations because of the other sensory losses. They may engage in a variety of creative patterns of self-stimulation. They use objects and people equally as tools to experience new and interesting types of sensations. For this reason it is sometimes difficult to tell for sure when a child is masturbating. Some people cannot believe that a young child would masturbate. A perfect example of this is a

child who started straddling a swing and who would become combative when staff tried to get her off the swing, even after a long period of time. Some of the staff thought that she was masturbating. Others, thinking she was too young to masturbate, felt it might be some other type of self-stimulation. Still others thought she was just being creative about swinging.

- *Family members and staff cannot reach agreement on how to address the behavior.*

Even when family members and staff are in agreement that masturbation is occurring, they may have very different ideas about how to address it. There are such intense personal values and beliefs tied to this topic. Sometimes it can be difficult to agree on what to do.

- *Masturbation is frequently not addressed in typical sexuality education policies or instruction.*

In a typical sexuality education curriculum, there is usually not much instruction provided about masturbation. Some curriculums specifically designed for people with developmental disabilities offer a bit more information. It is unusual to find a school policy that addresses this issue for the general population. The reality is, as a society, this is a topic that most people feel very uncomfortable discussing, let alone addressing. This is especially true when it relates to children and young adults.

- *Families look to professionals for help in addressing this issue.*

The family of a deaf-blind child may expect educational or medical professionals to help them address masturbation when it occurs with their child. Unfortunately, the professionals may not have any better idea what to do than the parents. This can leave the family feeling completely without support or a way to proceed.

- *Educational staff and other professionals may not feel prepared to address the issue.*

Sometimes the professionals think the parents should be responsible for guiding their child about this issue. This is especially true when the professionals do not have the answers either. The professionals may have had no training in college about sexuality education issues, and they are even less likely to have had training related to masturbation. Even at an in-service level, little training is provided to help teachers work with the child on this issue in the school setting.

An additional obstacle to addressing masturbation in children with deaf-blindness and developmental delays, is the attitude on the part of education and rehabilitation professionals that providing this instruction is not part of their job. It truly may not be what they envisioned a

teacher in a classroom or a rehabilitation setting doing. However, there are extreme social consequences for children or young adults with deaf-blindness who masturbate in public. For that reason alone, it is a critical area of social skills development that must be addressed.

Guidelines For Instruction and Intervention

TAKE RESPONSIBILITY

Personal values should not determine if masturbation issues are addressed. Rather, the child's need to succeed in society must be our motivation. As has been stated previously, many deaf-blind children in this group will experience normal puberty. Some will masturbate in public places including the home, the school, and community environments. If you ignore the behavior, then you are teaching the child that it is okay to masturbate whenever and wherever he or she feels inclined. This conduct puts him or her at serious risk in public. It may also cause him or her to lose employment, it may impact adult living arrangements, and limit inclusion in a variety of community activities. You must take responsibility to address the behavior when it occurs. The child cannot afford for you to look the other way or deny that it is happening.

FOLLOW PROCEDURES

As discussed in chapter 3, it is important to have a process in place for addressing any aspect of sexuality education because staff and family members need to understand their roles and responsibilities in that process. It is especially important for parents to be heavily involved in the development and implementation of instructional and intervention strategies to address masturbation.

Since there may be some increased risk of accusations of sexual abuse in dealing with a child who is masturbating, it is critical for staff and family to follow established procedures and keep a team approach when addressing incidents and concerns. They should have in-service training available that clarifies policies and values. All intervention should be well documented, understood, and agreed upon by the full team and school administrators for the protection of the child, the staff, and the family. No member of the educational team should try any type of intervention to address masturbation that has not been routed through the team and addressed in written policy and instructional guidelines.

ADDRESS THE PERCEIVED RELATIONSHIP BETWEEN MASTURBATION AND SEXUAL ABUSE

Frequently there is a perception that masturbation is an indicator of sexual abuse. Although there should always be reasonable concern about sexual abuse, it must be acknowledged that many deaf-blind children

with significant developmental delays discover masturbation on their own. These children may appear to masturbate more frequently than other children who are their age. There are other reasons likely for the behavior than sexual abuse. Most of these children are generally less private about the behavior. Often they have much more downtime without other sources of sensory stimulation. It is also not uncommon for these individuals to develop unusual methods of masturbating, again in part because they lack many of the inhibitions of their typical peers. As discussed later in Chapter 9, increased or unusual masturbation alone is not always a clear indicator of sexual abuse.

ANALYZE AND DEFINE THE BEHAVIOR

When designing intervention, there are three things you must do before determining what will work in addressing the behavior with the child.

- *Describe the behavior so there is a common understanding of when to intervene.*

Until everyone who is working with the child shares a common understanding of the exact behavior, it will be difficult to intervene. The educational team must be precise in describing the behaviors they are targeting for intervention. As mentioned earlier, it is important to be in agreement about what the child is doing when he or she masturbates.

- *Rule out medical conditions that may cause genital discomfort.*

A child with deaf-blindness is subject to the same diseases and conditions as any other person. Sometimes itching or discomfort from conditions like yeast infections may occur as a result of antibiotic use. There may be an allergic reaction to detergents or fabric softeners. Urinary tract infections may also cause the child to rub or scratch at the genital area. Make sure there is no medical problem contributing to the behavior.

- *Note settings, level of activity, objects, positions, or clothing that may trigger the behavior.*

It is not uncommon for a deaf-blind child to participate in masturbation if he or she has nothing else to do and is left alone for long periods of time. Sometimes a child might participate in masturbation only when wearing clothes that are very loose or perhaps very tight. Sitting or lying in a particular position, certain settings, or the presence of a particular object may be associated with the behavior. Listing the triggers for the child related to masturbation is critical to developing effective intervention.

USE EFFECTIVE INTERVENTION AND SUPPORT STRATEGIES

- *Increase supervision and activity levels for the child.*

One important strategy to use in addressing masturbation is to increase the level of supervision and the level of the child's activity. To be effective with any intervention strategies, you must first be able to redirect the child before he or she is fully engaged in the masturbation behavior. Once he or she has begun to masturbate, intervening becomes much more difficult. As mentioned earlier, masturbation often occurs because the child is left alone with little to keep him or her occupied outside his or her body. Making sure the child's day is well structured, well supervised, and full of interesting activities and interactions is one of the best ways to reduce an interest in masturbating.

- *Dress the child in complicated clothing.*

A very simple strategy for reducing masturbation behavior is to dress the child in complicated clothing that makes touching erogenous areas of the body more difficult. Consider the benefit of clothing that makes access to the body more difficult such as pants that zip and are belted, shirts that button and tuck, and so forth. Sweat suits and similar clothing may be more comfortable and easier to get in and out of, but they may also make it easier for the child to masturbate.

- *Address the triggers for masturbation proactively.*

If the child straddles a swing to masturbate, insist that he or she sit another way in the swing. This may even mean using a different type of swing that disallows the straddling position. If the child associates a mat in the gym with this activity, make sure he or she waits for his or her turn on a bench or in a chair. Whatever triggers the behavior, make sure you have a plan to avoid that trigger if possible or, if not, at least address the trigger proactively.

- *Develop strategies for times when the child may have to be alone.*

Sometimes deaf-blind children will masturbate when they go into the toilet or if they are left alone for long periods of time. While the restroom may appear to be an acceptable place for this behavior, consider what would happen if he or she did this in a public toilet, especially as an adult. A simple intervention is to have the child hold the toilet paper roll while using the toilet. It keeps the hands occupied and may be a reminder to keep the child focused on toileting. If the child has to be left alone at other times (e.g., while you are trying to get dinner ready) make sure that a variety of engaging toys or activities are available that can keep him or her occupied and busy.

- *Teach concepts to help the child learn to control the behavior.*

Provide a symbol for masturbation that communicates when and where masturbation may occur. If you are going to be successful in redirecting the behavior, you will need to let the child know that the desired behavior must wait. Having a symbol to use in a calendar system or to offer the child as you take him or her to her room is important. It might be an object symbol such as a vibrator, a small pillow from the bedroom, or something else the child associates with masturbation. Some of these children may be able to learn a sign that can be used to cue them such as "private" or "wait bed." Learning concepts of time such as "wait," "night," and "later" are important. Other concepts like "bed" and "home" help the child know where masturbation will be allowed. Whatever communication system your child uses, you must have some way to tell the child what is expected.

- *Be clear with the child about when and where masturbation is appropriate.*

When the child starts to masturbate at school, get the symbol for masturbation and talk about when and where this activity should take place. In some settings the strategy might be to redirect the child to a designated area within the school such as a restroom or a private screened area, and allow him or her a period of privacy. But it should be considered whether a typical child would be allowed to participate in this behavior during school time and also what would happen when the child is older and in other public settings. Will he or she be allowed downtime from work to go to the restroom to masturbate?

For these reasons, this behavior might be better restricted to home and the privacy of the child's bedroom. This will mean a bit more work for the staff at school in terms of redirecting the child and keeping him or her busy. Still, ideally the child's school day should be filled with interesting activities so that he or she does not have time to engage in this behavior or any other self-stimulation. Keeping a child from masturbating inappropriately will also mean additional work for the family. Instructional support or training for the family may need to be offered in the home. It also means that later on there may be additional work for caregivers in rehabilitation settings.

One other note about directing the child or young adult to an appropriate place to masturbate is that group homes and other institutional settings need to have a clear policy about what is an appropriate setting. It is unrealistic to try to eliminate this behavior. If an individual shares a bedroom, that may not be a good location. Perhaps a bathroom with a door lock or an occupied sign might be better. For many individuals with deaf-blindness and significant developmental disabilities, this is their primary way of releasing sexual tension. They must be provided a private and safe place when they need it.

- *Accept that it will take time to consistently intervene.*

It is not uncommon to hear the lament from teachers and parents alike, that they spend half their day redirecting one child. This may be true, and it may seem unrealistic to give one child so much individual time. However, this may be the most important lesson the child ever learns in terms of integration into the community and of his or her personal safety. It is worth the time that it takes to help the child with deaf-blindness learn the appropriate time and place for masturbating. If it takes an inordinate amount of time to intervene for a particular child, there may need to be one-on-one support provided throughout his or her day. The family may need to have help in developing activities that can be utilized during necessary downtimes at home. Additionally, there may need to be more supervision provided until the child learns that he or she must go to the privacy of the bedroom (or other location) to masturbate.

DEVELOP BEHAVIOR PLANS WHEN NECESSARY

For some children, masturbation in public places may have already become an ingrained behavior. When this occurs, it may help to develop a behavior plan that includes strategies that are both proactive (how to head the behavior off before it occurs) and reactive (how to respond to the behavior once it has occurred). It should clearly describe what the child is doing so every one is in agreement about the behavior that should be addressed. Triggers for this behavior should be noted so that family and staff can be alert to a possible incident and be prepared to intervene by redirecting or removing the trigger. Methods of diverting or redirecting should be consistent between home and school in order to effectively address the problem behavior. Having a good behavior plan allows everyone to remain calm while intervening and it reduces the power of the problem behavior.

ACCEPT THAT INTERVENTION CAN SHAPE THE BEHAVIOR BUT PROBABLY NOT EXTINGUISH IT

It is a reality that some children will masturbate. Based on the experience of teachers and parents and on research, it should be regarded as a natural behavior that the child typically discovers on his or her own. However, in the wrong time or place, it can have very serious consequences.

This behavior should not be punished. It is our belief that the goal should not be extinguishing the behavior. Punishing the child with deaf-blindness and developmental delays for masturbating is unfair. The child does not know he or she has done anything wrong. Clearly physical punishment is not an option in school settings. Besides that,

punishing the behavior typically only serves to escalate the behavior or to provoke a more aggressive behavior. Time out also is ineffective. It simply provides the child an additional opportunity to be alone with nothing to do. It is important to emphasize that the only way to appropriately address masturbation is to redirect the child to a private place through proactive intervention. If either the family or other members of the educational team oppose this approach to addressing masturbation issues, the ability of the educational team to address the problem is blocked.

EDUCATORS AND PROFESSIONALS SHOULD RESPECT THE FAMILY'S DESIRE TO ELIMINATE THE BEHAVIOR, BUT BE CLEAR ABOUT THEIR POSITION

If the family's goal is to eliminate masturbation, a program needs to be respectful of their feelings, but also straightforward about its position. Listen to what the family is saying and validate their beliefs and values. Explain that your program doesn't know how to eliminate masturbation from the child's behavior, but you can work to help control that behavior during school hours. If the family wants the behavior to be punished, remind them that school/agency policy regarding punishment prevents you from supporting their wishes. Also be sure to share with them information about the occurrence of masturbation in children with and without developmental disabilities. It may also be helpful to connect them with other parents who have been successful in addressing masturbation with their children or who at least are willing to share concerns in a supportive atmosphere.

TAKE PRECAUTIONS TO PREVENT THE MASTURBATION FROM BECOMING ABUSIVE TO OTHERS

While masturbation may not be an indicator of abuse in children with deaf-blindness and significant developmental delays, these individuals may be at increased risk for both abusing others and being abused by those who would use them as partners in their own masturbation strategies. Be alert to the possibility of these situations, especially in settings where several individuals are left alone for long periods of time and in proximity. Take steps to prevent opportunities for abuse.

MAKE SURE NO ONE CROSSES A LINE INTO SEXUAL BEHAVIOR WITH THE CHILD

Sometimes, if not carefully thought out, interventions can be inappropriate. Some people may even consider the intervention to be participating in a sexual act or sexually abusing the child. Be sure to examine the literature on sexual abuse that is listed in the final chapter in this book. There is a fine line that should never be crossed. For example, giving a young man a sexually explicit magazine to replace the National Geo-

graphic he has incorporated on his own into his masturbation strategies would be considered abuse based on the strict definition of the term. Even keeping the bedroom door open or staying in the room to supervise the masturbating child might be considered crossing a line. However, there may be times when supervising a child is necessary if his or her behaviors involve the risk of injury. The best protection lies in clear policy and guidelines, team planning, and communication between school and home.

School policy should provide clear guidance about intervention. Staff must have in-service instruction about steps to reduce the risk of inadvertently engaging in what would be considered sexual behavior with a child or young adult. Parents should also protect themselves from accusations of abuse.

Probably one of the most effective forms of protection for both parents and educational staff related to accusations of sexual abuse is participating in an educational team process. Working with others to identify and discuss issues and to document intervention keeps everything out in the open. If someone calls an action into question, the team should be able to provide a clear explanation for what happened and why.

MAKE SURE THE STAFF RESPECTS THE CHILD'S DIGNITY AND KEEPS MATTERS CONFIDENTIAL

Masturbation should not be a source of humor or gossip for anyone working with the child. The behaviors should be discussed in a professional manner that always respects the dignity of the child. Information should be kept confidential and not shared with those outside the child's team any more than is absolutely necessary.

Troubleshooting Issues About Masturbation

Issues	Things to try
The child masturbates in public places.	◆ Identify possible triggers such as position, clothing, objects, etc. ◆ Make sure there are not medical issues contributing to the behavior. ◆ Develop appropriate intervention strategies such as changing the position, removing the trigger object, and dressing the child in more complicated clothing to reduce the behavior. ◆ Increase the supervision and be prepared to redirect the child. ◆ Give the child a symbol to represent masturbation and tell him to "wait home" or "wait bedroom."
The child uses an unwilling peer as part of his/her masturbation strategy.	◆ Intervene and stop the behavior immediately. ◆ Share the incident with the team immediately, follow established policy related to reporting, and develop a plan to prevent a future occurrence of the event. ◆ Increase supervision.
The child masturbates in a way that may be dangerous.	◆ Remove any object that is dangerous and make sure it is completely unavailable to him/her. ◆ Increase supervision.

Conclusion

Masturbation is a difficult issue for most parents and professionals who work with children who are deaf-blind and have additional disabilities. There is a natural tendency to want to ignore or avoid dealing with this behavior. However, given the harsh response of society to people who break the rules about public masturbation, it is critical that masturbation not be ignored. The school and family must work together to formulate effective programming and intervention strategies to address a child's masturbation behaviors. They must provide the intensive individual intervention that may initially be required to redirect this behavior to a more appropriate expression. The child's future integration into society as well as his or her personal safety is at risk if this is not done.

Chapter 8

Sexual Health Care

This chapter will examine the issues and suggest intervention and instructional strategies related to providing good sexual health care. These issues include male and female wellness checks, prevention and treatment of sexually transmitted diseases and other conditions affecting the reproductive system, birth control, and sterilization. Although the primary focus is on deaf-blind individuals with significant developmental delays, parts of this information may also be helpful to parents of individuals who do not have additional developmental disabilities.

Issues About Good Sexual Health Care

ISSUES FOR THE CHILD OR YOUTH WITH DEAF-BLINDNESS

- *Certain etiologies may have implications for sexual health.*

Although not all etiologies that are associated with deaf-blindness have implications for sexual health, there are some that do. For example, children with CHARGE syndrome may have genital hypoplasia (Hefner and Davenport, 1997). Bardet-Biedl syndromes may result in genital hypoplasia or vaginal atresia. Trisomy 13 individuals my have undescended testes, abnormal scrotum, or a uterus with horn-shaped branches. Some individuals with Cornelia de Lange syndrome seem to have excessive pain associated with menses. It is important for medical personnel and parents to become familiar with the sexual health issues related to any syndrome.

- *A child with deaf-blindness and significant developmental delays may not be able to successfully communicate problems about his or her health.*

It is not uncommon to hear parents of children in this group say, "If he could only tell me he was hurting or where he was hurting." Unfortunately, most of these children may only be able to express these concerns through their behaviors. Furthermore, they may only choose to do so when the condition has become unbearable. Sometimes caregivers may not be aware of problems until individuals have become quite ill.

Even deaf-blind children with more sophisticated communications skills may not recognize a need to tell someone that he or she does not feel well.

- *These individuals may be uncooperative about participating in medical procedures and exams.*

Many deaf-blind children have had hundreds of medical examinations and procedures by the time they reach puberty. Anything associated with these experiences, right down to the smell of the doctor's office, can elicit some very challenging behaviors, even in otherwise gentle children. It is no wonder then that some children may be uncooperative in participating in medical procedures and examinations related to their sexual health needs. Most non-disabled individuals also find these procedures somewhat uncomfortable and stressful. Unlike a typical peer though, the deaf-blind child or young adult does not have the ability to easily learn about the procedure in advance. They cannot discuss their fears with someone who can reassure them. They simply act out.

- *Sexual contacts with others may lead to pregnancy or sexual transmitted disease.*

As discussed later in the chapter on sexual abuse, children with deaf-blindness and significant developmental delays are at increased risk for abuse. This abuse, whether perpetrated by a sexual predator or by another person with developmental disabilities, may lead to sexually transmitted disease (STD) or even pregnancy. The same is true if the individual is a consenting partner in a sexual activity.

SOCIETY'S ISSUES

- *Society does not think that individuals with deaf-blindness and developmental disabilities are at risk for sexually transmitted diseases or medical conditions that impact reproductive systems.*

Society as a whole has a tendency to think of people with disabilities as being asexual, even people who only have mobility impairments or mild intellectual disabilities. This perception affects access to quality health care that includes wellness checks, testing for diseases of the reproductive system, birth control, and so forth. People with disabilities often are not included in public discussion about sterilization and reproduction, the right to control medical decisions about sexual or reproductive functions, or accessing treatment and prevention of sexually transmitted diseases.

Deaf-blind people who have additional cognitive delays need access to birth control and support to address reproductive issues. They are also at risk for sexually transmitted diseases. For individuals with the most

severe disabilities, STD's often occur as a result of sexual abuse. Some children may also be at increased genetic risk for certain diseases if other family members are at risk. Diseases such as ovarian, uterine, breast, prostate, and testicular cancers can happen to anyone. Individuals are not excluded from having more benign conditions such as yeast infections, jock itch, urinary and bladder infections or other similar problems just because they are disabled. The general public tends to overlook these facts. This causes an additional burden for deaf-blind individuals.

ISSUES FOR PARENTS AND PROFESSIONALS

- *Parents and professionals may be focused on more demanding medical needs.*

Families and professionals give a great deal of time and attention to addressing multiple medical issues for their child or student. Because so much energy goes into general medical management, just to keep the child healthy enough to go to school and participate in a quality home life, sexual health issues often are overlooked. Syndromes that cause chronic health problems such as CHARGE, Cornelia de Lange, or Crit du Chat, can consume a great deal of a family's time, energy, and finances. It is understandable that they might procrastinate about reproductive or sexual health issues.

- *Like the rest of society, parents and professionals may view the child or young adult as asexual.*

Both parents and professionals may only see a child's disabilities rather than his or her age and gender. When confronted with the changes brought on by puberty, parents may not plan the same types of wellness checks as they would for a child without disabilities. Both parents and professionals might disregard or misinterpret symptoms for sexually transmitted diseases or conditions affecting sexual organs. They may view behaviors that would alert them to symptoms of disease or infection as just part of the child's disability. For example, caregivers may not think about yeast infections when they see a young deaf-blind woman pulling at her slacks or panties. They may assume that she is self-stimulating or masturbating.

- *Families may look to professionals for help in addressing sexual health issues.*

Many families assume that doctors will let them know what types of wellness checks their son or daughter needs. They believe that the doctors will know to consider as possibilities sexually transmitted diseases, and other conditions. Parents may assume their doctor will be familiar with all aspects of a particular etiology, including those affecting sexual

health. The reality is that this is not always the case. Parents and caregivers sometimes have to be strong advocates in order to focus the health care system on addressing these issues.

Parents also look to the educational and rehabilitation professionals for support in addressing these health-related issues with their child. They need the educational support to help them to build concepts that can prepare a child for a wellness exam, to help the child alert them to pain or discomfort, and to prepare the child for hospitalization and/or surgical procedures. They need information about sexually transmitted diseases, laws related to medical consent, and so forth. Most educational and rehabilitation professionals are not prepared to offer this type of support.

- *Education and rehabilitation professionals may feel unprepared to address these issues.*

Like parents, most professionals are unfamiliar with symptoms of sexually transmitted diseases. They may not know about specific sexual and reproductive issues associated with certain etiologies. They probably have not had any training or experience in addressing these types of issues in instructional settings. Sometimes, they may feel that it is not part of their role to address these issues, but rather something that should be handled by the family or medical staff.

- *Both families and educational or rehabilitation professionals may be unaware of the laws related to medical consent, birth control, surgical sterilization, or pregnancy.*

When a child is under eighteen, the parents have certain rights related to medical care. After an individual with deaf-blindness and developmental disabilities becomes a legal adult, guardianship must be sought by parents to allow them continued control over some medical issues. They do not continue to have rights related to the use of birth control, surgical sterilization, or pregnancy. Control over these matters is determined by other laws and is not considered in the same light as other more typical medical issues. Most families and professionals have little or no knowledge of the laws addressing sterilization or birth control and how they affect the child or young adult. Also, these laws constantly change and they vary from state to state.

Guidelines For Instruction and Intervention

ACKNOWLEDGE YOUR CHILD'S SEXUAL HEALTH NEEDS

The first step towards acknowledging your child's sexual health needs is to remember that your child is sexual rather than asexual. Until you can begin to see your deaf-blind child as a person who is a sexual being, you can easily overlook his or her needs in this area. Remember that this is the aspect of physical development in which your child is most likely to resemble typical peers.

ADVOCATE WITHIN THE MEDICAL COMMUNITY TO ENSURE THE PROVISION OF APPROPRIATE SERVICES

As a parent or caregiver, you will need to become familiar with the types of medical exams that are appropriate for an individual your child's age. Search for a doctor who is willing to collaborate with you in planning for these examinations and who will give you and your child the extra time and attention that may be needed. Talking with other parents of children with special needs may help you to locate the kind of physician you want.

Just as you plan for vaccinations, regular dental exams, and other routine wellness activities, include planning for exams that address your child's sexual health. Your doctor or nurse can provide some timelines for when these exams are typically done. They should include pelvic and breast exams beginning in your daughter's late teens. As she ages (about age forty) mammograms are recommended. Your son should have regular testicular exams. As he ages (about age fifty) you may want to include prostate exams as well. Discuss with your doctors what is involved in these exams, the age that is recommended for beginning them for a person without disabilities, and how frequently they should be repeated. They should be included as part of regular physicals for the individual with deaf-blindness and significant developmental delays.

UNDERSTAND HOW THE ETIOLOGY AFFECTS SEXUAL DEVELOPMENT AND SEXUAL HEALTH

There are specific syndromes that may result in deaf-blindness, and many of these have aspects that affect sexual development and sexual health. Some syndromes may typically have early onset of puberty; others may result in delayed puberty or puberty that is absent without hormone therapy. Some syndromes have behavioral characteristics that result in excessive anxiety or pain. These behavioral traits may escalate with the onset of puberty, the pain of menses, and so forth. Get as much information as possible about the impact of your child's etiology on his or her sexual development and sexual health. Make sure your doctor and other caregivers are aware of these issues too. Good resources for finding this type of information are national support groups or foundations that focus on particular syndromes or conditions or NORD (National Organization for Rare Disorders). Contact information for NORD may be found in Chapter 10 (page 118).

SHARE A COMPLETE FAMILY MEDICAL HISTORY WITH YOUR DOCTOR

The child with deaf-blindness and developmental disabilities does not escape increased risks for medical conditions that may hereditary. For example, if there is a high incidence of ovarian cancer in your family's

history, your physician should know that information. It may not mean that your deaf-blind daughter will have ovarian cancer at some time, but just like your other daughters, she may need to be watched more closely for the condition. Also, a thorough family medical history may be helpful in determining safer birth control medications and may have impact on other types of medical treatment.

KNOW THE LAWS THAT RELATE TO MANAGING YOUR CHILD'S SEXUAL HEALTH

Children in this group may never be able to manage their own health or make independent decisions about birth control, reproduction, pregnancy, medical intervention, and so forth. However, parents should not assume that they always call the shots for their child. There are certain health-related issues that can be addressed by a parent only until the child turns eighteen. At that point, some type of guardianship may give parents partial control over medical interventions. It is important to know your state's laws about medical decisions that are specific to sexual health. For example, there are abortion laws specific to every state. If your daughter were to become pregnant, you may or may not be able to make a decision for her about an abortion. Additionally, surgical sterilization may not be permitted just because you request it. Although many parents feel that this is the appropriate way to ensure the deaf-blind child's health, there are some important legal considerations of which parents should be aware related to this issue. The American Academy of Pediatrics' Committee on Bioethics advises that physicians be aware of state law dealing with the age of consent and the sterilization of minors with developmental disabilities. They write:

> *The age of consent, including that for surgical procedures, varies from state to state. Some minors may be old enough under applicable laws to be considered eligible to agree to sterilization if otherwise capable of doing so. In such cases, a careful clinical assessment of decision-making capacity must be performed by a professional skilled in and experienced with evaluating the capabilities of persons with disabilities, such as a psychiatrist, licensed psychologist, social worker, or pediatrician. Adolescents who have been declared by judges to be mentally competent for the purpose of accepting or refusing sterilization are entitled to make whatever decision they believe furthers their own interests. In some states, laws or court precedent forbid procedures aimed primarily at accomplishing sterilization solely on the authorization of parents or other legal guardians consulting with appropriate physicians and surgeons. When the involved parties believe surgical sterilization to be the best option, application to the courts may provide the only lawful means to accomplish that goal. Physicians and surgeons should be familiar with the law that applies to the jurisdictions where they practice.*

Committee on Bioethics, American Academy of Pediatrics - Sterilization of Minors With Developmental Disabilities, Pediatrics, August, 1999, 104(2) p337-341.

The laws related to sexual health, consent, and personal liability can be overwhelming to both parents and caregivers. It is understandable that they may sometimes feel it is easier to avoid the issue altogether. After all, maybe nothing will happen. It is important to remember that failure to address a child or young adult's health needs may be considered neglect. Parents and other caregivers must understand their responsibilities and limitations under the various federal, state, and local laws.

Typically your doctor should be able to help you get this information. Other resources include lawyers who are experienced in guardianship issues; national, state and local Association for Persons with Mental Retardation (ARC), your state's child protection and advocacy agency, and your state's parent training and information center. For your protection, as well as for the protection of your deaf-blind child, learn what your state laws are related to managing your child's sexual health.

If you are a professional working with an adult residential program, your program should have very clear policy relating to the management of clients' sexual health-care needs. This includes defining how decisions about medical treatment, birth control, consensual sex, and pregnancy will be handled, the rights of the parents/guardian, and the rights of the individual with deaf-blindness and additional developmental disabilities.

TAP INTO THE EXPERTISE OF SEASONED PROFESSIONALS AND PARENTS WITH OLDER CHILDREN

Parents can feel very alone when trying to manage their child's sexual health. It is always helpful to talk to another parent who has already dealt with these issues. He or she may not have the answer that is right for you and your child but may be able to help you clarify your concerns and point you in the direction of resources. Parent support organizations such as National Family Association for Deaf-Blind (NFADB) or ARC, state-level support groups, and local groups are a good place to go to make these connections.

There are also educational and medical professionals who are knowledgeable about issues and resources. Bring your concerns to your child's educational or rehabilitation team. Talk to your family doctor, Planned Parenthood, or school nurse. The more you know, the easier the decisions will become and the better your choices will be. Silence and worry will not get you or your child with deaf-blindness very far.

Educational and rehabilitation professionals should also make use of these resources. The more information they have, the better prepared they will be to help the family and the young adult with these issues.

INCLUDE IEP GOALS THAT HELP PREPARE FOR MEDICAL EXAMINATIONS

Like any other area of sexuality, managing sexual health issues is a skill that an individual with disabilities needs to live a happy and healthy adult life. It is appropriate to focus on skill development related to these needs as a part of the child's educational program. The goals of instruction should be very limited. Typically he or she will not be making decisions about birth control, medical procedures, and so forth. Instead the goal for instruction should be to reduce anxiety and to gain better cooperation during examination and treatment.

DEVELOP CONCEPTS

There are specific concepts that the child with deaf-blindness and significant developmental delays will need even if he or she is not capable of participating in sexual health-care activities. For example, not understanding what is happening during a medical examination of any kind can be traumatic for the child. Learning concepts such as "penis," "vagina," "breast," "doctor," "nurse," "examination table," "calm," "wait," "touch," "lie down," "temperature," "blood pressure," and so forth are important. If the child understands these concepts it will be easier to explain what will happen during an examination.

RELEASE STAFF TO SUPPORT THE CHILD DURING THE EXAMINATION

At the family's request, schools should consider allowing release time for staff to support families during these exams. This experience is one that can be used by educators and parents to work on many important life skills for their child or young adult and it will involve some planning. For some school programs, it may also require persuading higher level school administrators to support the effort. But the benefits to the medical staff, the family, and most importantly to the child are worth it. Since participation in medical examinations and procedures is probably certain to be a regular part of deaf-blind individuals' lives, this level of instructional support leads to important adult outcomes.

TAKE A DISTRACTION TO THE EXAM

Bring along a favorite toy or object to distract the child when he or she becomes anxious during a doctor visit. For example, one young woman was very found of plastic flowers. When she arrived at the doctor's office, her parent gave her a new bunch of flowers to hold in her hands. They talked to her to keep her attention engaged on the flowers rather than on the doctor's activities.

WHEN THE EXAM IS FINISHED, HELP THE CHILD DEAL WITH HIS OR HER FEELINGS

These examinations have a big impact on some children and young adults. It is important to take time after the visit to talk about what happened. Collect items from the visit that can be used in a story bag or box to review what happened, then placed in a finished box on a calendar. This often helps the child know that the exam will not happen again today, and allows everyone to get back to a normal routine. For children who are able to use more sophisticated calendar systems, looking forward in time to discuss that there are no more examinations scheduled in the near future can be helpful as well. Set aside opportunities to review and share the experience, affirming what has happened, how well the child did, and that the exam is finished.

USE ROUTINES

Developing a routine around a visit to the doctor can reduce anxiety for the child. This type of routine is good for any kind of visit, not just ones related to sexual health. Before you take the child in for a particular examination, find out what will happen during this visit, and incorporate the details into a step-by-step routine.

Practice the routine by going through some of the steps with the child. For example, practice changing into an examination gown, having his or her blood pressure checked, and getting on and off an examination table. The school nurse could assist with the practice of these activities. If you don't have a school nurse, talk to your family doctor about setting up some practice visits to the office. Ask the school to allow educational staff to plan an individual "field trip" to the doctor's office. The teacher can then support the child and you in becoming familiar with the examination room and the devices that may be experienced during the visit.

USE CALENDAR SYSTEMS

If the child uses any type of calendar system, represent the activity with some type of symbol. This can help the child anticipate when visits might occur and when they are finished. Also if he or she can anticipate a favorite activity after successfully completing the examination, getting through the event will be easier. For example, when you sense anxiety building during any part of the exam, you can reassure the child by reminding him or her, "Wait, calm, lie down. Finish, then ice cream." Bring along the symbol for ice cream and show it to him or her. Don't hesitate to use bribery. This is one time when his or her favorite reward should be a guarantee.

DEVELOP INSTRUCTIONAL UNITS FOR CERTAIN CHILDREN

Some children benefit from a unit related to medical exams. For the student who can categorize and who already has the ability to represent information in an abstract manner (pictures, print, signing, etc.) the use of instructional units is important. Since male and female wellness checks (pelvic, breast, testicular, and prostate examinations) are such a different experience from other types of examinations, the deaf-blind individual can benefit greatly from some advance preparation. You could begin an examination unit even at a young age and limit the focus to temperature, blood pressure checks, and so forth. As the young adult nears the age for a breast, pelvic, testicular, digital rectal examination, these new aspects could be added to the routine.

Sample Unit on Preparing for a Well-Woman or Well-Man Check

Concepts To Learn:

1. Names of the body parts involved in the examination (breasts, vagina, testicles, rectum, etc.) and other concepts such as doctor, nurse, examination, table, lay down, gown, lamp, calm, wait, hurt, change, on, off, touch.
2. You change into a gown for this type of visit. You will put your clothes back on soon and leave. (For those individuals who associate the gown with being admitted to the hospital, assure them that there is no hospital stay involved in this procedure.)
3. Other men/women the student knows have these visits as well. (Mom, Dad, the school nurse, the teacher, Uncle Bob, Aunt Kay).

Activities For Instruction:

1. Using an anatomically correct figure, simulate going through the doctor's visit step-by-step and discuss. Have the child assist with each step of the activity, and allow plenty of time for him/her to examine the devices that will be used.

Include the Following Steps for Both Well-Woman and Well-Man Checks:

- Take off the figure's clothes.
- Change it into a gown.
- Put the figure's clothes nearby.
- Put the figure on the examination table.
- Complete the basic steps involved in any visit on the figure (taking temperature and blood pressure, listening to the heart).
- Tell the figure to "lay down" and discuss how the figure must stay still and be calm.

Steps for Well-Woman Check:

- Let the student know that the doctor will pull down the gown to check each breast. Discuss in terms such as, "wait, patience, calm, doctor okay touch

breast." Demonstrate on the figure and then let the student practice this step with the figure.

- Put the figure's feet in stirrups. Discuss in terms such as, "feet up, wait, calm, doctor okay touch." Let the student examine how the feet are placed.
- If the doctor is going to use a lamp, have one there to use. Let the student explore the lamp, turn it on, and discuss in terms such as "doctor light look, okay."
- Using the figure, show the student that the doctor will be examining the pelvic area and discuss with her in terms such as "wait, doctor touch okay, look vagina, hurt little, calm, patience." Depending on the student, you may use a swab to insert in the vagina of the figure and discuss in terms such as "calm, patience, doctor touch in vagina, hurt little, okay." If there is a speculum available for the young woman to examine, allow her to do so and explain how it will be used. Use the correct vocabulary according to child's communication level: vagina, vulva, etc. You may let the student be the "doctor" if she can make that association.
- Tell the figure and have the child tell the figure, "Finish."
- Get the figure up, change its clothes, and say good-bye to the doctor.
- Talk about where the figure will go to have a special reward for being good at the doctor. Be sure to use the reward that will mean the most to the young woman.

Include the Following Steps for a Well-Man Check:

- Lay the figure on the table and elevate the right leg. Discuss in terms such as "leg up, wait." Feel the scrotum area for the right testicle. Discuss in terms such as "wait, patience, calm, doctor touch testicle, okay."
- Roll the testicle between the thumb and fingers to examine. Discuss in terms of concepts like "wait, calm, patience, doctor hurt little." You may let the student be the "doctor" if he can make that association.
- Lower the figure's leg and repeat with left leg.
- Tell the figure and have the child tell the figure, "Finish."
- Get the figure up, change clothes, and say good-bye to the doctor.
- Talk about where the figure will go to have a special reward for being good at the doctor. Be sure to use the reward that will mean the most to the young man.

Other Instructional Activities for Both Male and Female Deaf-Blind students

1. Borrow a gown from the doctor. Take the child to the school nurse's office. Have him or her change into the gown, and place the street clothes on a chair. If possible have him or her get on the examination table or a couch. Ask the nurse to go through some of the routine checks like taking the temperature and blood pressure, listening to the heart, and so forth. Have the student change back into his or her clothes. Go for a special reward. You

may want to start with one part such as changing clothes, then later add another part like taking his or her temperature, then later add on another part.

2. If the student has enough vision and picture recognition skills, draw sequence pictures that show the basic steps of an examination and discuss each one. Have the child try to find the correct picture representing each step, and then talk about it. Arrange the cards in the correct order as you discuss what happens next.

3. Make a field trip to a doctor's office so the student can see the office and talk through what is going to happen. Take the sequence pictures or object symbols with you and locate the real items (gown, table, stirrups, swab, speculum, etc.) and discuss what will happen. If possible, meet the doctor and nurse. Go for a special reward.

4. Schedule the visit in the student's calendar so he or she can be prepared for the visit. Note that it is a special day, but just part of it will be different from normal. Reassure the child that things will return to normal after the doctor visit is finished.

5. After the student is familiar with the process and has the vocabulary, have a familiar same-sex adult talk with the student about having an examination. Make sure this person is prepared to discuss it and can focus on concepts and vocabulary the student is familiar with through your lessons. This adult can assure the student that he or she has had the exam and it was okay. List other people he or she knows who have had the examination as well. It is also a good idea to let the student know the examination is "private" so it will not become a constant topic with the general public.

Conclusion

Regular attention to a child or young adult's sexual health-care needs is critical. Parents and educators should make it a focus of instruction and intervention for the child with deaf-blindness and significant developmental delays. Parents, rehabilitation staff, and other caregivers must be aware of the laws related to managing sexual health issues, providing birth control, pursuing surgical sterilization, and addressing pregnancy. They should discuss concerns with the young adult's doctor and plan for his or her needs now and in the future. In making choices about their child's sexuality, parents can benefit from discussing their concerns with other parents and with caring professionals from the medical, legal, and educational communities. They should advocate for quality health education programs as well as the child's right to have good sexual health care.

Troubleshooting Issues about Sexual Health

Issue	Things to try
The student becomes agitated the minute he/she enters a doctor's office.	◆ Using a routine or unit approach, practice the steps that will take place for an examination. ◆ Have a symbol representing the examination and a favorite activity, and discuss the sequence of events using a daily calendar. ◆ Plan a field trip to the doctor's office just to meet the doctor, see the room, and if possible do some of the preliminary examination tasks such as checking blood pressure. (You may want to make several trips, adding a few new and more stressful items each visit.) Go immediately to the reward activity. Take home mementos of the field trip and them make into a storybook or story bag to review regularly with the student.
The student resists during an examination.	◆ Have familiar trusted people go with the student to the exam. ◆ Select a doctor who will work with you and allow for such extras as a "field trip," having an educational support person in the examination room, and so forth. ◆ Take along favorite objects to distract the child during the exam. ◆ Schedule the appointment for a time of day when the student is typically most calm and cooperative (e.g., after lunch). ◆ Stand near the student during the entire exam, talk with him or her reassuringly, and try to engage him or her with a favorite toy or object. As part of the conversation, remind the child of the next (favorite) activity after the exam using symbols or signs. ◆ Have the doctor or nurse be prepared to stop the procedure if necessary, to allow you to calm the student and review the picture sequence. Then, try again.

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Chapter 9

Sexual Abuse

Perhaps one of the most difficult issues to discuss in sexuality education is sexual abuse. It is also one of the most important issues. For the child or young adult with deaf-blindness and significant developmental delays, there are two areas of vulnerability. The first, a parent's greatest fear, is that their son or daughter will be the victim of a sexual predator. The second is that their son or daughter will be viewed as a sexual predator or behave in a way that makes others think he or she is sexually assaulting someone.

How Is Sexual Abuse Defined?

Sexual abuse includes a wide range of sexual activities that are forced upon someone. Sexual abuse consists of sexually inappropriate and non-consensual actions, such as exposure to sexual materials (such as pornography), the use of inappropriate sexual remarks/language, not respecting the privacy (physical boundaries) of a child or individual (e.g., walking in on someone while dressing or in the bathroom), fondling, exhibitionism, oral sex and forced sexual intercourse (rape).

(Reynolds, 2000)

Most people think of sexual abuse as rape or penetration, but it may include a variety of other behaviors as well. Some actions such as exposure to sexual materials, inappropriate language, exhibitionism or failure to respect privacy, may not have the obvious impact on the child that forced sexual intercourse or oral sex would have. If any of these actions are tolerated with a child or young adult with deaf-blindness and significant developmental delays that are not tolerated with the non-disabled child, a message is sent that deaf-blind individuals are not entitled to the same rights and respect as other human beings. Such a notion contributes to the child's vulnerability.

The other side of the coin is that the deaf-blind children or young adults might exhibit behaviors that may be perceived as being sexually aggressive and this makes them vulnerable. While their motivation may be innocent, the behaviors, if they involve other individuals, especially those

younger or also disabled, can be considered abuse. Although prosecution and conviction on abuse charges is unlikely for these individuals, dire consequences such as institutionalization or arrest are not.

How Often Does Sexual Abuse Occur?

It is inconceivable to most people that anyone would victimize a child or young adult with disabilities, especially if the person is deaf-blind and has developmental delays. Research shows that it does happen, and it happens a lot more than one might think.

Research tells us that if a child has an intellectual disability, she is three to five times more likely to be sexually victimized than any other member of any other group. The exact statistics aren't important here, but you need to be aware that almost all of this abuse has happened in supposedly safe places for people with disabilities, done by those people who are supposed to be safe people. The very places where you expect protection have been the places where abuse has occurred, and the very people who you expect to be protectors have been the people who have done the abuse. (Schwier and Hingsburger, 2000.)

More than 90 percent of people with developmental disabilities will experience sexual abuse at some point in their lives. Forty-nine percent will experience 10 or more abusive incidents (Valenti-Hein & Schwartz, 1995). Other studies suggest that 39 to 68 percent of girls and 16 to 30 percent of boys will be sexually abused before their eighteenth birthday. The likelihood of rape is staggering: 15,000 to 19,000 of people with developmental disabilities are raped each year in the United States (Sobsey, in Reynolds, 2000).

When you add to the intellectual disabilities the unique issues related to deaf-blindness, these children and young adults are a very vulnerable group.

Who Are The Abusers?

The point should be emphasized that although there may be individuals who are drawn to professions with easy access to people who are especially vulnerable, the fields of education and human service are not riddled with people who are pedophiles (persons who see children as sexual objects) or sexual predators. Deaf-blind children who have significant developmental disabilities do not necessarily live in families with a higher incidence of sexual abuse. However, since these children and young adults tend to have limited numbers of people with whom they come into contact, if abuse does occur, it is likely to be perpetrated by someone who has regular opportunities to be alone with them. That means that sexual abusers can be professionals, family members, friends, other individuals with disabilities, or anyone who has regular access to the children and opportunities to be alone with them. Again, this possibility should be balanced with the knowledge that the majority of people who have contact with children are perfectly safe and trustworthy.

Issues About Sexual Abuse For The Child Or Young Adult Who Is Deaf-Blind

Deaf-blindness creates some unique issues for children and young adults related to sexual abuse. It is important to understand these issues in order to protect these children and young adults.

LANGUAGE AND CONCEPT DEFICITS

Children and young adults with deaf-blindness and developmental delays may lack the language and concepts needed to prevent being victimized. For example, they may not understand that some people might hurt them or that it is not all right for people to touch their genitals. They probably do not know that they should tell someone trustworthy if someone does try to do this to them. They also may lack the communication skills to tell anyone if they have been victimized, even if they did know it was wrong.

Individuals in this group are more likely to be victims of sexual abuse than their typical peers are. However, it is not always easy to know when abuse occurs for these children or young adults. Some of the primary indicators of abuse in the typical population are behavioral changes: depression, withdrawal, sexually inappropriate behavior, noncompliance, seizures, excessive crying, regression to childlike or infantile behaviors, fear of being touched, and so forth. For many deaf-blind children with developmental delays, these behaviors are not necessarily atypical. These might not be clear indicators of sexual abuse.

Even if a parent or caregiver picks up on behavioral changes, getting the child to communicate what has happened, if he or she perceives it as something wrong, is unlikely. The fact is, unless there is physical evidence of sexual abuse such as bruising in the genital areas, sexually transmitted disease, unexplained pregnancy, genital discomfort, etc., no one is likely to know abuse has occurred.

INABILITY TO ASSIST IN AN INVESTIGATION OR TESTIFY IN COURT

Children and young adults with may not be able to share information with investigators that results in the arrest of a pedophile or sexual predator. They may also not be viable witnesses if the sexual predator is brought to court. This is another reason why they are especially vulnerable to abusers.

THE USE OF TOUCH IN INSTRUCTION AND CAREGIVING

Children and young adults with deaf-blindness more frequently experience touch by people for the purposes of communication, assistance with travel, and support in caregiving routines than do their nondisabled peers or even some peers with other types of disabilities. They may lack a sense of what is appropriate and inappropriate touch or concepts about private areas of the body, where people may not touch without permission.

SEXUAL ABUSE MAY NOT BE PERCEIVED AS AVERSIVE BY THE VICTIM

Deaf-blind children and young adults may not perceive some abuse as aversive and may actually find the contact pleasurable. Because they lack the sense of social taboos, they may not experience the same negative emotions about the abuse as a typical peer would. They are sometimes the perfect "willing victim."

THEIR VULNERABILITY TO ABUSE IS DENIED

Children and young adults in this group may be viewed as not being at risk for sexual abuse. This happens because the public does not often recognize that sexual predators victimize people with disabilities. People think it unlikely that individuals would want to hurt someone who is disabled. They are in denial that pedophiles or sexual predators are not uncommon and do look for easy targets.

DEAF-BLIND CHILDREN ARE FREQUENTLY VERY COMPLIANT

This particular group of children and young adults may be naturally compliant because of their limited experience in their environment. Frequently they are not given opportunities to exercise personal choice about much of anything, but especially about who interacts with them and how. They may also be compliant because they are physically unable to protest or stop the actions of others.

ISOLATION, A TYPICAL OUTCOME OF DEAF-BLINDNESS, INCREASES THE RISK OF ABUSE

Unless the people in their lives work hard to create circles of support, children and young adults with deaf-blindness and developmental delays are at increased risk for isolation. This is a known factor that increases the risk of anyone's being abused.

POOR SOCIAL SKILLS DEVELOPMENT AND NATURAL CURIOSITY OFTEN LEADS TO BEHAVIORS THAT APPEAR SEXUALLY AGGRESSIVE TO OTHERS

Sometimes children and young adults in this group may exhibit behaviors of a sexual nature that may seem aggressive. This happens because their natural curiosity and limited vision and hearing lead them to move in too close, to touch inappropriately, or to use taste and smell to identify people. At other times they may use social skills that are inappropriate for their age or the situation. An individual in his or her twenties or thirties who kisses a stranger or young child in the parking lot of the grocery store will probably be viewed as sexually aggressive. This action, though innocent, could result in the filing of abuse charges. Even if it did not have such dire consequences, this behavior certainly could prevent him or her from holding a job at that store. It might also make others keep their distance.

SOME DEAF-BLIND INDIVIDUALS ATTEMPT SEXUAL ACTS WITH PARTNERS WHO DO NOT GIVE THEIR CONSENT

Some deaf-blind children or young adults who also have developmental disabilities may act in a way that is sexually abusive to another person without any sense of this behavior being abusive. For example, they may try to kiss someone who does not want to be kissed, or in another more extreme case, they may attempt to masturbate with an unwilling partner. That unwilling partner may be another person with a disability who cannot defend him or herself or resist these advances. The offending individual may not be able to understand the significance of his or her actions, but the consequences may be arrest, lawsuits, and/or abuse charges.

Guidelines For Instruction and Intervention

We do not want you to feel helpless when confronted with the challenges that deaf-blindness brings to keeping an individual safe from sexual abuse. There are some things families and professionals can do.

BE AWARE THAT YOU MUST PROVIDE PROTECTION

The reality for most children in this group is that they may not ever be taught to defend themselves from sexual predators. Even children and young adults with pretty good communication skills (for example, individuals with basic reading and math skills who can discuss and understand rules) are typically only too willing to go with anyone anywhere. It does not matter to them if the person is a stranger, and they do not consider what that person might want to do to them. They may not be able to make the subtle distinctions about who is a "stranger." In one instance, several students were shown pictures of "strangers" during a lesson. In this activity they were supposed to sort people into categories of "people they knew" versus "strangers." When the activity was repeated the next day, however, the strangers had become people they knew. From their perspective, they had seen the pictures the day before and so they "knew" these people.

The best protection for most individuals with deaf-blindness comes from the vigilance and support of trustworthy family members, friends, and professionals. Vigilance and advocacy are key to keeping them safe.

KNOW THE BACKGROUNDS OF INDIVIDUALS WHO HAVE ACCESS TO THE CHILD

Individuals with this combination of disabilities will always depend on a variety of service providers and others for care-giving activities. Parents can feel that they are in a no-win situation. On the one hand, they need to bring service providers and educators into their child's world but they also want keep him safe from those who might want to hurt him. However, there are steps that can be taken to protect the child.

Knowing the background of individuals who have access to the child is an important step in preventing sexual abuse. This includes professionals who work directly with him or her and those with limited access such as a cafeteria worker, bus driver, etc. Schools and other programs generally run criminal background checks on some employees. Parents should feel free to ask if these checks have been done on all the people working with their child.

For a small fee, parents may pay to have a criminal background check run on a person by contacting their state's department of public safety (DPS). Information about sexual offenders may also be found on the Sexual Offenders Registry. These checks do help and sometimes just the threat of having a criminal background check done frightens off a sexual predator. Remember, however, that the DPS checks only account for crimes in that state for which a person has been convicted and generally will not mention incidents in that state in which there were no arrests or convictions. Nor will it show arrests and convictions that occurred in another state. The Sexual Offenders Registry is not necessarily kept current so it may not include recent charges. Higher levels of screening are possible but may not always be realistic. The Personal Safety Awareness Center of the organization SafePlace publishes a fact sheet entitled "Screening Practices for Hiring People to Work with Individuals with Disabilities in Need of Support" that can provide guidance to families or programs about screening individuals. This fact sheet and other informational materials may be requested by contacting:

SafePlace
P. O. Box 19454
Austin, Texas 78760
(512) 356-1599 (voice) or (512) 482-0691 (TDD)
Web site: http://www.austin-safeplace.org/services/psac

Parents and school administrators should trust their instincts when it comes to suspecting possible pedophiles or sexual predators. If you are not sure about a person (and perhaps even if you are), provide close supervision of the employee.

Children and adults with deaf-blindness and significant developmental delays need to trust others in their lives to protect them. Parents, schools, and programs serving individuals with deaf-blindness cannot turn a blind eye to the reality of their vulnerability. Caregivers' awareness is their protection.

ACCESS RESOURCES TO HELP YOUR TEAM LEARN MORE ABOUT SEXUAL ABUSE

SafePlace also sponsors the Personal Safety Awareness Center and offers a resource lending library featuring books, curriculum kits, videos, audiotapes, anatomically correct figures, models, games, journals, and other materials relating to abuse and violence prevention, sexuality education, and personal safety for people with disabilities, families, and professionals. The library currently features over 250 items that are available for checkout in person or by mail within the United States. Although these do not specifically address children with deaf-blindness, there is useful information to be gleaned from many of them. Other resources worth checking out include:

National Domestic Violence Hotline
3616 Far West Boulevard, Suite 101-297
Austin, TX 78731-3074
Hotline: 1-800-799-SAFE
http://www.ndvh.org/

RAINN: Rape, Abuse, and Incest National Network Hotline
1-800-656-HOPE
http://www.rainn.org/

International Coalition on Abuse and Disability
http://www.quasar.ualberta.ca/ddc/ICAD/icad.html

The National Committee to Prevent Child Abuse
332 S. Michigan Avenue, Suite 1600
Chicago, IL 60604
1-800-555-3748
http://www.preventchildabuse.org/

REDUCE ISOLATION

Schools and families can work to make sure that there are few opportunities for the child to be alone with someone in a location where abuse could occur. For example, having a private changing area in a public bathroom at school makes it more difficult for the sexual predator to feel safe. There is a chance that another student or staff member could come into the restroom. In group-living situations, having more than one staff person with residents at all times is a good idea. However, in small apartment-living situations, this level of support may not be possible.

As the child gets older and the family ages, often times there is no one to be the advocate and protector of the individual. Parents should begin early in the life of the child to build a large network of people who care

what happens to their son or daughter. Having many people to check on the welfare of the individual increases the likelihood that changes in behavior or appearance signaling possible abuse will be questioned. Also, if a person has people who care about him constantly popping in and out of his home, a potential abuser may feel less secure and be deterred.

RESPECT YOUR CHILD'S DIGNITY AND MODESTY, AND REQUIRE OTHERS TO DO THE SAME

Parents should always model the way that they want others to treat their child. If you do not respect the child's dignity and modesty, some others may not either. In caregiving activities and other interactions, use discretion. Think about where you change diapers, how you dress your child, how you touch him or her, and so forth. Model the approaches you want to see others using with him or her. You are key in setting the standards for treatment of your child by others.

Educational and rehabilitation programs generally should take their lead from the parents. At times, however, they may need to guide parents who may not be aware of the long-term consequences of their interactions with the child. Having clear policy regarding caregiving routines helps to ensure that the child with deaf-blindness is never treated as if his modesty or dignity is not important. For example, even as a toddler, a child should be appropriately dressed in public. This is sometimes difficult or may take extra time, but it is important. Think about the age at which it would not be appropriate for a typical child to walk around in only a diaper or to be disrobed in a restroom without the stall door closed. Treat an individual with deaf-blindness and developmental delays just as you would his or her typical peer. When you ignore principles of dignity and modesty, you are sending the message that the individual is somehow less valuable or maybe even less human. It may say to some twisted mind that sexually abusing this individual really is not a serious offense.

MAKE IT A PRACTICE TO ASK THE CHILD'S PERMISSION

School programs and family members need to remember to ask permission from the child before doing things with him or to him. That might mean for some children a momentary pause after presenting an object cue representing the next step in a routine in order to see if he is okay with things. Caregivers should, as much as possible, recognize that the child's pushing our hands away or protesting with a cry is a clear "no." Stop and at least offer some option or choice. Having well-crafted caregiving routines that provide opportunities for a child to exercise some control over what is happening to him or her is very important.

TEACH OTHERS TO USE APPROPRIATE BEHAVIOR WITH YOUR CHILD

Do not allow strangers to touch your child without permission. Well-meaning people often feel very free to hug or kiss a child. Ask them to shake hands or use some other more neutral greeting. Save hugs and kisses for close family and friends. This helps to model for the child a behavior that is likely to be more acceptable to the public at large, and it will keep him from later being punished for being too familiar.

TEACH THE CHILD TO USE APPROPRIATE BEHAVIORS WHEN INTERACTING WITH OTHERS

Sometimes a child or young adult with disabilities will do things like hugging a perfect stranger, kissing a small child, or touching a woman's breast or a man's groin area. Most of the time, the individual is unaware that he or she has acted inappropriately. Perhaps the family and educational staff have never taught the child that this is inappropriate. Families should be cautious about allowing their child to be too familiar with people. Teach handshakes and distant hugs or pats. Calmly redirect the child's attempts to touch people inappropriately. Work with your educational team to develop intervention plans for when the child's doing something that can put him or her at risk. This includes behaviors that are currently risky or may prove to be risky in the future.

When a child is capable of learning social rules about behavior, they should be taught. If the child is not capable of controlling his or her behavior, extra effort must be made to reduce the opportunities for victimizing someone else. This means closer supervision and possibly the development of a formal behavior plan to address the behavior.

RESIST TEACHING A CHILD TO BE OVERLY COMPLIANT

Although many deaf-blind individuals would not be able to defend themselves from a determined predator, very quiet and compliant children are at greater risk. Yet, often when working with deaf-blind children, caregivers seem intent on having them comply with the demands of anyone who interacts with them. The children are offered too few opportunities to exercise any control or choice in their daily lives. If they respond to a rough touch or unwanted direction with any kind of resistance, they are perceived as the ones with the problem. The real problem of inappropriate behavior lies with those who seek to control the children.

IF APPROPRIATE, TEACH SAFETY RULES

Some individuals with deaf-blindness and developmental delays are capable of learning some social "rules" about appropriate behavior that

may provide them some measure of protection. These are individuals who also have the ability to understand representational information in an abstract manner (pictures, signing, print) and who can do complex categorization based on attributes other than purely physical traits. For these individuals, every effort should be made to teach them these rules. For example, they might learn to categorize people who would be safe to ask for help versus those who might not be safe to ask.

If the individual can make some judgments about who is or who isn't safe to approach for help, spend time discussing this issue in real-life situations. For example, when you are in the mall or at school, have the child show you whom he would go to for help if someone were bothering or hurting him. Have the child practice finding a security guard, a principal, a policeman, a store clerk, a manager, etc. Give the child a card to use in emergencies to get help. The card should include the child's name (and name sign if appropriate), have a note that indicates a need for help, offer an explanation of the individual's disability, and provide an emergency contact phone number and address. Set up practice situations with support from these community members and let the child practice using the card to get assistance. This can be beneficial in a number of situations, not just when abuse occurs.

A few additional instructional strategies related to personal safety follow:

- Teach what is and what is not appropriate touch (see Chapter 5, page 43).
- Teach the concepts of public and private (see Chapter 4. page 34).
- Provide many opportunities to practice safety skills through role-play and through community-based experiences.
- Teach the child how to get someone's attention, yell for help, or solicit assistance using whatever communication method works best for him or her.
- Help him to understand appropriate personal boundaries and provide strategies for him to tell someone "no" and "stop."
- Help him make a list of trusted adults whom he can "tell" if someone bothers him.
- Teach him not to go off with someone alone unless you say it is okay.
- Offer him opportunities to take a self-defense class.

There are many good training tools for people with intellectual disabilities that can be adapted for the individual with deaf-blindness. These

may also be useful for some students with significant developmental delays. Chapter 10 (page 109) lists some of these materials. School programs should collect materials for use by families and educational staff.

TEACH COMMUNICATION SKILLS THAT HELP THE PERSON "TELL" ABOUT ABUSE

Whenever possible, teach deaf-blind children key vocabulary and concepts that enable them to report to someone if they "hurt" and where the pain is located. If they can point to the body part that hurts, that may be enough, but it would also be good if they could give a sign or signal for the particular body part. Dr. Pearl Tait and Carol Kessler describe in their article "The Way We Get Babies: A Tactual Sex Education Program" (1978) figures that are used in their sexual education program to help blind children understand sexual intercourse. The article tells how these figures can be made out of fabric and other materials. Using these figures may be beneficial for some children to both learn and reference specific body parts or to "tell" about incidents they have experienced. Though this type of "evidence" might not hold up in a courtroom, it could help trusted adults protect the child from someone who is abusing him or her.

Learning the name signs of individuals who work with them is also a good idea. Family members and caregivers should identify themselves to the child by the appropriate sign or signal whenever they approach the child for an interaction. The greater the child's ability to communicate "who" does what with them, the greater threat he is to a potential sexual predator.

BE ALERT TO EVIDENCE OF ABUSE AND REPORT IT TO AUTHORITIES FOR INVESTIGATION

For most of the individuals focused on in this book, though they may be motivated to tell someone about sexual abuse, they probably would lack the ability to do it. They also probably could not participate in an investigation, give testimony, or offer any support to the efforts of the justice system to arrest and prosecute the perpetrator of the sexual abuse. Because of the vision and hearing loss and their developmental delays, the reliability of their testimony would not be sufficient for most judicial purposes. So what is the point of reporting abuse? The answer is provided in the following quotation from Leigh Ann Reynold's article "People with Mental Retardation and Sexual Abuse" (2000):

> *"Abusers typically abuse as many as 70 people before ever getting caught. Without reporting, there can be no prosecution of offenders or treatment for victims. Underreporting of sexual abusive incidents involving people with disabilities has in the past, and continues to be, a major obstacle in preventing sexual abuse."*

The very act of reporting may save the child (or other children in a program) from becoming a repeated victim of abuse. When pedophiles, or other sexual predators, know that the people surrounding the child or young adult with deaf-blindness are both vigilant and unafraid to report the abuse, they are perhaps less likely to seek a job working with the child (or the children in a particular program). Additionally, reporting a sexual predator may not get him convicted this time, but it may alert authorities when incidents in his proximity occur in the future.

When educational or rehabilitation staff observe behavioral or physical evidence that indicates there might have been sexual abuse, they must follow up on it. The school or program will have a standard policy for handling suspected abuse as required by law. All staff members working with the child should have regular training about how to report suspected abuse. They should follow their school's policy to the letter to protect the child, the school program, and themselves.

Parents who have concerns about behavioral or physical problems that, in their minds, indicate sexual abuse should contact child protective services and seek guidance about pursuing their concerns. If the suspected abuser is a family member, they may need to contact someone in a domestic abuse organization (such as Battered Women's Center, SafePlace) to learn how to keep the child and themselves safe while the abuse allegation is being handled.

It is important to point out that once a report of suspected sexual abuse has been made, a series of actions has been started that will not be stopped without an investigation. Everyone in the child's life will be suspect as the system rightly moves in to protect the child. That is why it is so important to move forward systematically and responsibly once you suspect abuse. There is often a need to share your concerns with just one other person. It is understandable to have this need when such a situation occurs, but it is a mistake. If that person is not responsible and shares details with one other person, innocent people can be destroyed. Even after suspected abuse is ultimately disproved, the allegation lingers. Following a strict procedure for reporting is critical. If school or rehabilitation staff needs support in handling their feelings about the situation, it should be provided in a way that keeps the suspected abuse confidential. Parents should also use discretion in sharing their concerns outside of the system that is meant to protect the child.

Both staff and family members should carefully document the evidence they observe that causes them to think a child is being sexually abused. School or organization policy will guide the professional on how to proceed. Parents should photograph bruises, scratches, or other physical signs. They should write down when they first noticed the problem.

They should also note any behavioral changes that support their concerns and when they first noticed the change. The family may want to consult with the child's pediatrician or the family doctor about their concerns and have the child examined. Parents may also want to share with authorities investigating the abuse a list of all the people at school, at home, and in the community who might have private access to the child.

If you suspect that a child or adult is being or has been sexually, physically, or emotionally abused, call your state's protective and regulatory services hotline.

PROTECT AND SUPPORT THE "GOOD GUYS"

It is okay to be suspicious of anyone who finds many opportunities to be alone with a child. *But*, it is important to remember that most people who work with these children are the "good guys." The reality is that many training and caregiving activities for child with deaf-blindness and developmental disabilities must often be provided in isolated settings. Therefore, educational and human service programs must protect and support staff charged with carrying out these activities.

Professionals who work with children and/or people with deaf-blindness and developmental delays are at risk for accusations of abuse if they are not mindful of even the appearance of impropriety. The best protection they have from accusations is a well-planned and open team approach to sexuality instruction and intervention. They must be able to frankly discuss concerns, instruction and intervention strategies, and incidents related to sexuality. They must have clear guidelines and policy to follow and the complete support of their administrators. Administrators must take specific steps to keep a staff person from being in vulnerable positions. Some steps that can be taken to reduce the risks for everyone include:

- Using a team process for planning instruction and day-to-day intervention;
- Making sure that the family has input into the team process;
- Posting schedules of where the child is throughout the day and with whom;
- Providing training to ensure staff sensitivity to the issues and guidance about how situations are to be handled; and
- Creating an environment in which both staff and families can feel safe in bringing up concerns and creatively finding solutions.

Parents or family members are also at risk for being accused of sexual

abuse. One step that parents may want to pursue to protect themselves from false accusations of sexual abuse is to have a strong working relationship with the child's pediatrician or physician's assistant. A doctor who regularly sees the child with deaf-blindness and who keeps a well-documented history of medical concerns may be a resource for any investigation. He or she may be able to respond to charges that are brought forward by professionals or even another parent in a custody dispute. Of course, having a consistent physician who really knows the child or the parent may not be possible in this day of managed health care and HMOs.

Like the professionals, parent's best protection against false accusations may be the development of a good sexuality education program for their son or daughter. An understanding of the unique issues that deaf-blindness brings related to sexual abuse should be part of any sexuality education program. Having a team of people with whom parents can openly share concerns and collaborate to find solutions is just as important for the parents as for the professionals.

It is unfortunate that those involved in the teaching and care of deaf-blind individuals must be so cautious, but realistically this is the case . Anyone who works with these individuals is at risk for charges of sexual abuse if situations are not handled professionally. The children's safety must be the highest priority. At the same time, steps must be taken to protect innocent family members and professionals from false accusations.

Conclusion

In an ideal world the awful reality of sexual abuse would not exist. In this world it does exist, and children and adults with deaf-blindness and significant developmental delays are at very great risk for being abused. The only true protection for them comes from the attentiveness and the actions of safe adults who are looking out for their welfare. These individuals cannot afford to have those responsible for them bury their heads in the sand when it comes to sexual abuse. Rather, caretakers must be vigilant and outspoken about their safety.

References

Reynolds, L. A. (2000). People with mental retardation and sexual abuse. ***The ARC's Q & A on People with Mental Retardation & Sexual Abuse.*** **Available at: http://thearc.org/faqs/Sexabuse.html**

Personal Safety Awareness Center (2000). Screening practices for hiring people to work with individuals with disabilities in need of support. (Fact Sheet). Austin, TX. Available at: http://www.austin-safeplace.org/services/psac/index.htm

Schwier, K. M., & Hingsburger, D. (2000). *Sexuality: Your sons and daughters with intellectual disabilities.* Baltimore, Maryland. Paul H. Brooks Publishing. pp 134.

Tait, Pearl E., Ph.D., & Kessler, C., M..A. (March, 1978). The way we get babies: A tactual sex education program. *The New Outlook,* pp 116-120.

Chapter 10

Resources and Readings Related to Sexuality Education

This chapter provides parents, as well as educational and human service programs, a place to start in developing a library of resources and materials for instruction and intervention. This book has taken only a beginning look at this topic.

There is much more to learn and much more that needs to be written about the unique issues of providing sexuality education to the individual who is deaf-blind and has significant developmental delays. Also, there is more to be discussed about providing sexuality education to the deaf-blind person who does not have developmental delays. Many excellent materials were developed in the 1970s, but these should be updated and new materials developed. Parents and professionals should advocate for this by requesting that older publications be updated and/or reprinted and by contacting some of the publishers listed to make their needs known.

Articles, Books, and Curriculum

The list of resources we have included here purposely lists only a few of the good resources that have been developed. Parents and professionals do not have time to review all the available literature, so this list is meant to provide a starting place that allows them to add to their library a little at a time. The articles and books included here will list other good materials in their references.

One of the criteria for selecting an article, book, or product as a resource was the ease with which it could be located. So we primarily include products that can be requested through public libraries, current web sites, and local bookstores. The articles listed should all be available through DB-LINK. Some of the books and curriculums may be more difficult to find but they are worth tracking down. State deaf-blind projects, schools for the deaf or blind, college/university special education programs and/or disability organizations (such as ARC and United Cerebral Palsy) may help to locate these older materials. Publishers who get enough calls from parents and professionals will perhaps consider reprinting those that are out of print.

Readability was another criterion for selection of particular items. In these, jargon is minimal, and they are clear and easy to follow.

Relevance was the final criterion used. While some of the included books and articles were not written specifically about children with deaf-blindness and developmental delays, the relevance to this population is obvious.

The list includes a number of web sites and on-line materials. It is important to note that these change frequently and may disappear overnight. Articles found on web sites were typically referenced separately from the site with the hope that it might be located even if the web site has disappeared.

Most materials included could easily be found at the time this paper was written. In cases where some materials are no longer available, it may be necessary to search bookstores and libraries or contact educational material supply companies to locate other items that will serve the same purpose. The list includes descriptions that will hopefully aide in the selection of good substitutions.

Articles

DEAF-BLIND SPECIFIC

Belote, Maurice (1997). Taking the fear out of sex education. Individuals in a changing society: 1997 National Conference on Deafblindness workshop proceedings, 1, 50-65. Boston; Hilton/Perkins Program.

This paper from California's Deaf-Blind Services provides an overview of the issues and describes components of the process for developing a program. The focus is on individuals without significant developmental delays.

Hamilton, Toby (Fall, 1979). Sexuality in deaf blind persons. Sexuality and Disability, 2, 238-246.

This is a good article that discusses the issues of sexuality education for individuals with deaf-blindness. It contrasts the effects of visual impairment, deafness, and deaf-blindness related to sexuality education.

Merkin, Lewis, and Smith, Marilyn J., (1995). A community based model providing services for deaf and deaf-blind victims of sexual assault and domestic violence. Sexuality and Disability, 13, 2, 97-106.

This article describes how the Seattle program, *Abused Deaf Women's Advocacy Services*, addresses domestic violence and sexual assault. This agency is run by deaf and deaf-blind people, and all staff and volunteers there are fluent in American Sign Language.

Miles, Barbara (1999). Talking the language of hands to the hands. (Fact sheet) DB-LINK, Monmouth, OR: The National Information Clearinghouse on Children Who Are Deaf-Blind. Available in downloadable text via DB-Link web site at http://www.tr.wou.edu/dblink/hands2.htm.

Although this paper is not about sexuality education, it is worth reading to gain an understanding of the different role that touch plays in the life of a child with deaf blindness.

Miller, Tom (1997). Social/sex education for children and youth who are deafblind. The individual in a changing society: 1997 National Conference on Deafblindness workshop proceedings, 2, 558-592. Boston: Hilton/Perkins Program.

This article is only one of many good ones from Tom Miller. It was selected because it is easily obtained from DB-LINK, is thorough in discussing the issues, suggests core curriculum for sexuality education, and touches on policy issues.

Neff, Jan. (1978). Sexuality and the deaf-blind individual. Proceedings: Sex Education for Deaf-Blind Children and Adolescents, Sheldon, J. (Ed.). New York: Mid-Atlantic North and Caribbean Regional Center for Services to Deaf-Blind Children.

Most of Jan Neff's writings come from the seventies, but her work is among the best. This one makes the best case for why sexuality education should begin early and be a standard part of instruction for every child with deaf-blindness.

NON-DEAF-BLIND SPECIFIC

Appendix I: Discussion paper: Developing protocols to help vulnerable adults (2000). Adults with Vulnerability Web site Available at: http://library.utoronto.ca/www/aging/awvhome.htm

Appendix II: Protocol worksheet (2000). Adults with Vulnerability Web site Available at: http://library.utoronto.ca/www/aging/awvhome.htm

These are two portions of a larger document that makes up the Adults with Vulnerability Web site. They contain good basic information about developing protocols for addressing abuse and neglect with vulnerable populations, including the elderly and individuals with disabilities.

Committee on Bioethics, American Academy of Pediatrics (August 1999). Sterilization of minors with developmental disabilities. Pediatrics, Part 1 of 2, 104(2), 337-340.

This is the best of just a few papers on the topic of sterilization of indi-

viduals with developmental disabilities. This is a must read for any parent considering that option for their child with deaf-blindness and developmental delays. It provides good information on assessing the individual's capacity to make decisions about sexual intercourse. The article discusses the consequences of reproduction for the person and any child he or she might produce, as well as other options to address the consequences of sexual maturation. Most importantly, it shares information related to local, state, and federal laws about sterilization.

Personal Safety Awareness Center (2000). Identifiers of caregiver abuse (Fact sheet). Austin, TX: SafePlace Available at web site: http://www.austin-safeplace.org/services/psac/index.htm

Personal Safety Awareness Center (2000). Screening practices for hiring people to work with individuals with disabilities in need of support (Fact sheet). Austin, TX Available at Web site: http://www.austin-safeplace.org/services/psac/index.htm.

Personal Safety Awareness Center (2000). Tips on what to do if the child discloses abuse (Fact sheet). Austin, TX Available at website: http://www.austin-safeplace.org/services/psac/index.htm.

These are three of the best fact sheets from SafePlace. These one-page information sheets might be a good accompaniment to a policy and procedures manual, for use in in-service training with parents and professionals.

Kupper, Lisa, Ambler, Lana, and Valdivieso, Carol (1992). Sexuality education for children and youth with disabilities. NICHY News Digest, #ND17. Available at Web site: http://www.nichy.org or by contacting NICHY at 1-800-695-0285 (voice/TTY).

This is probably one of the most thorough documents on sexuality education for people with developmental disabilities. It is especially parent friendly in its design and offers excellent references after each section. This is a must read for anyone thinking about sexuality education for the child with disabilities.

Learning about: Sexual abuse of children. News from Advocates for Deaf-Blind, Winter 1995-1996.

This letter is from a parent whose child is blind and has Down Syndrome. The letter discusses the occurrence of sexual abuse in a residential setting. Pamela Ryan from Perkins School for the Blind responds to this parent's letter and discusses how typical abuse occurs.

NFADB mail call (1996). News from Advocates for Deaf-Blind, 3(1), 10-11.

This article is a response to "Learning about: Sexual abuse of children" and discusses the way one incident of sexual abuse was handled by the police and the criminal justice system. It also includes the author's advice to other families dealing with this type of situation.

Noll, Joann (December 1996). Puberty comes anyway. Exceptional Parent, 61-62.

Written by a parent, this article captures some of the typical parents' concerns about their daughters' sexual development. Joann makes some good points about why sexuality education is important.

Reynolds, Leigh Ann (2000). People with mental retardation and sexual abuse. The ARC's Q & A on People with Mental Retardation & Sexual Abuse Available at Web site: http://thearc.org/faqs/Sexabuse.html

This article provides good basic information about the signs of sexual abuse and what to do if abuse is suspected, and it also offers some resources. A note of caution related to the signs of sexual abuse: These may not all be clear indicators of sexual abuse in a child with deaf-blindness and developmental delays. (Please read chapter 9, in this paper "Sexual Abuse".)

Stavis, Paul F. (2000). More thinking about sex: Three suggestions for drafting program guidelines and three case studies. NYS Commission of Quality Care Web site Available at http://www.cqc.state.ny.us/cc71.htm

Stavis, Paul F. (2000). Provider's liability for sexual activity which causes injury, pregnancy or a sexually transmitted disease. NYS Commission of Quality Care Web site Available at http://www.cqc.state.ny.us/cc54.htm

Stavis, Paul F. (2000). Recent developments in law and recent data on sexual incidents policy considerations for providers. NYS Commission of Quality Care Web site Available at http://www.cqc.state.ny.us/cc66a.htm

Stavis, Paul F. (2000). Sexual activity and the law of consent. NYS Commission of Quality Care Web site Available at http://www.cqc.state.ny.us/cc50.htm

These are just four of the good articles from the New York State Commission of Quality Care Web site, written by Paul Stavis, counsel to the commission. There is not much available on legal issues related to sexu-

ality and people with disabilities. These articles are very easy to understand and offer good basic information on sexuality and the law. Programs serving individuals with disabilities should especially benefit from reviewing this material.

Tait, Pearl E., and Kessler, Carol (March 1976). The way we get babies: A tactual sex education program. The New Outlook, 116-120.

This is a good article about a program to help teach about reproduction. It includes a pattern for making anatomically correct cloth figures.

Walker-Hirsch, Leslie, and Acton, Gitta (June 1995). Sexuality and young adults with developmental disabilities. Nevada Dual Sensory Impairment Project Newsletter, 6(3), 3-6.

This article takes a good look at the need that children with developmental disabilities have for support from their parents and other caring adults in providing sexuality education. It helps parents understand how important it is to celebrate their children's developing sexuality. It also offers suggestions for helping children find friendships and later, romantic relationships, which can reduce the occurrence of loneliness and isolation in their adult lives.

Books and Curriculums

DEAF-BLIND SPECIFIC

Cadigan, Ellen, and Geuss, Roslye Roberts (1981). Sex education: A curriculum for the deaf-blind. Watertown, MA: Perkins School for the Blind.

This is the only deaf-blind-specific sexuality education curriculum, and it is very good. Units include self-identity, anatomy of the reproductive systems, human reproduction, growth from birth to puberty, adolescence, and medical aspects such as personal health care and hygiene.

Miller, Tom (1999). Social/sex education for children and youth who are deafblind. In John M. McInnes (Ed.), A guide to planning and support for individuals who are deafblind, pp. 201-226. Toronto: University of Toronto Press.

This chapter of the McInnes book is another good resource from Tom Miller. It includes an overview of the problem of providing sexuality education, aspects to consider in providing social and sexuality education, what and when to teach, techniques for instruction, policy development, and so forth.

NON-DEAF-BLIND SPECIFIC

Bell, Ruth (1998). Changing bodies, changing lives: A book for Teens on Sex and Relationships. New York: Random House.

This book was written for teens and gives great information about the human body and sexuality. It is a good encyclopedia of sexual information, which parents and programs may want to reference. The book also covers a variety of related topics that may not have immediate application for individuals who are deaf-blind with developmental delays, but it would be of interest to deaf-blind teens who are not developmentally delayed. These topics include substance abuse, living with violence, dealing with unplanned pregnancy, and getting involved in making a difference.

Brown, Gail T., Carney, Pat, Cortis, John M., Metz, Lori L., and Petrie, Anne M. (1985). Human sexuality handbook: Guiding people toward positive expressions of sexuality. Springfield, MA: The Association for Community Living.

This book was recommended by Tom Miller and was originally developed as a procedural guide for adults with developmental disabilities and for staff working with them in residential settings. This book may be useful especially in developing policy and guidelines for programs.

Burt, John J., and Meeks, Linda Brower (1989). Education for sexuality: Concepts and programs for teaching (3rd Ed.). Dubuque, IA: Wm. C. Brown Publishers.

This is probably the best book that offers solid, basic information about all aspects of sexuality. It also contains a great deal of information about typical sexuality education concepts for each grade-level, beginning at kindergarten and going through high school. There is also a section in the back with black-and-white line drawings that may be useful for instructing some students with adequate vision and ability.

Kempton, Winifred (1988). The Life Horizons Curriculum. Santa Barbara, CA: James Stanfield Company, Inc. Phone: (800) 421-6534. Web site: http://www.stanfield.com.

This is an exceptional curriculum developed in the 1970s and reprinted. It contains a series of color slides with accompanying text for use in instruction. Most of the slides are photographs of real people, although there are a few slides of drawings that show inner anatomical structures. Some of these slides are explicit; however, because they are slides, programs and parents can select only the slides they want to use in instruction. For some children with deaf-blindness, these materials would be invaluable in providing instruction. Following are the components of the curriculum:

Part I: Sex education for persons with special needs: The physiological and emotional aspects of being male and female.

This set contains a videotape where Winifred Kempton explains how and why the series was developed, discusses the importance of sexuality education, and speaks about issues in educating individuals with mental retardation about sexuality. Some of the information may seem a bit dated, but it is still a very good discussion that will help both parents and professionals feel better about their role in providing sexuality education. The slides in this part include sets on parts of the body, sexual life cycle, human reproduction, birth control, and sexual health. Text to explain each slide is included in a booklet.

Part II: Sex education for persons with special needs: The moral, social, and legal aspects of sexuality.

Like Part I, Part II includes a series of slides and accompanying text. The sets of slides include building self-esteem and establishing relationships, male social-sexual behavior, female social-sexual behavior, dating, marriage, parenting, and preventing/coping with sexual abuse.

Nilsson, Lennart (1993). How was I born? New York: Dell Publishing.

This is a children's book with excellent color photographs about pregnancy, childbirth, and the first days of a newborn's life. For certain students with enough vision and understanding of picture representations, the pictures in this book could be used in instruction to explain where the baby comes from, breastfeeding, and so forth.

Pearse, Patricia (1988). See how you grow. Hauppauge, NY: Barron's Educational Series, Inc.

This book is appealing because of the lift-the-flap format that shows a woman's belly with a baby inside. For some children with deaf-blindness, certain portions of this book could be used in instruction.

Rouse, Geraldine Rodriguez, and Birch, Carol Pence (1991). Socialization and sex education: The Life Horizons Curriculum Module. Santa Barbara, CA: James Stanfield Company, Inc. Phone: (800) 421-6534. Web site: http://www.stanfield.com.

This curriculum was designed for use with the Life Horizons sets. It contains thirty-one lessons around sexuality issues. Each lesson includes the following sections: overview/teacher preparation, objective, objective in student terms, purpose in student terms, vocabulary, instructional activities, closure, parent/guardian contact, and additional activities. Each lesson has a series of question cards to generate discussion. For certain children with deaf-blindness this set could be used

without modification, but for most deaf-blind children with significant developmental delays, the primary benefit of this package would be to help the teacher/parent think of the concepts that should be taught. The lessons/activities may require considerable modification depending on the child's language level, cognitive abilities, and sensory impairments.

Schwier, Karin Melberg, and Hingsburger, Dave (2000). Sexuality: Your sons and daughters with intellectual disabilities. Baltimore, MD: Paul H. Brooks Publishing, Co.

This is a must read for parents of children with developmental disabilities. It will help you to understand the importance of sexuality education and help you to feel more comfortable with the topic. Much of the information comes from parents and people with developmental or intellectual disabilities making it particularly enjoyable to read.

A Word About Information From The Internet

There are a number of good Web sites for a variety of informational needs. Although some of the most current information was on the Internet, parents and professionals should realize that information from these sources changes daily. Also be aware that a Web site that exists today may not exist tomorrow. Web sites are included because they were very helpful. Hopefully, they will be in existence when you begin your study. Do not be afraid to use the Internet to seek out information. You will likely find some weird sites, but there is much useful information to be accessed as well. One good strategy is to search links from disability-specific or government Web sites.

SafePlace
http://www.austin-safeplace.org/

This organization sponsors the Personal Safety Awareness Center, and there is some excellent information available from it including the three great fact sheets listed under non-deaf-blind specific articles.

Family Village
http://www.familyvillage.wisc.edu/index.html

This is a great source for disability related information. It offers links to information on sexuality and disability. When you get to the index by going to the address listed above, click on the "Library" icon, then "General Information" link, and look for the "Sexuality and Disabilities" link. You may also want to check out the "Abuse and Disability" link as well.

Health Scout
http://www.healthscout.com

This Web site on health issues has several links to information on human sexuality, wellness information, and medical encyclopedias. It changes frequently but is worth exploring.

International Coalition on Abuse and Disability
http://www.quasar.ualberta.ca/ddc/ICAD/icad.html

This site is part of the J. P. Das Developmental Disabilities Centre, University of Alberta, Edmonton, Alberta. It is especially interesting because it seems to function as a forum in which to advocate for research and social reform addressing issues of abuse for people with disabilities, including the elderly. Dick Sobsey, who has done a great deal of work in this area, is involved with this Web site. It includes ICAD-L an electronic mail network on the topic of abuse and disability. ICAD began in October of 1993. Currently about 200 people in twelve countries have joined. They include researchers, clinicians, people with disabilities, parents, and others interested in this topic.

National Organization for Rare Disorders (NORD)
http://www.rarediseases.org

This website has good information about syndromes and conditions, and is a good resource for medical information and support groups for specific conditions. It also describes any sexual health concerns related to a specific syndrome of condition.

Resource List: Sexuality and Disability
http://www.realtime.net/austinrapecrisis/HTML/psac-lst.htm

This is one of the links from the Family Village Web site that offers an extensive listing of materials and resources.

Royal Adelaide Hospital, Sexually Transmitted Disease Clinic
http://www.stdservices.on.net/std/definition.htm

This page of the Web site offers good information on sexually transmitted diseases. Warning to parents and professionals: There are explicit pictures of the symptoms of the various STDs.

Sexuality Information and Education Council of the United States (SIECUS)
http://www.siecus.org

This Web site has much to recommend it as a general resource on sexuality education. They also have a disability-specific link. The annotated bibliographies that can be found at http://www.siecus.org/pubs/biblio/bibs0009.html are particularly worth checking out.

Instructional Materials: Models and Videotapes

Because of the unique learning styles of children with deaf-blindness and significant developmental delays, good instructional materials are invaluable. Unfortunately, there are not many ready-made products that work for these children. However, there are a few that can be used with some adaptation for certain children.

FIGURES AND MODELS

One of the problems with models is that they tend to be of only a portion of the body (pelvic area, torso, etc.). This can be too abstract for some children with deaf-blindness, especially those with significant developmental delays. However, for certain children with deaf-blindness, some models may be useful in conjunction with other instructional materials. Most useful are anatomically correct figures. These figures can be made using the patterns included in the article by Pearl Tait, or ready-made figures from Teach-A-Bodies can be ordered.

Teach-A-Bodies Dolls, Teach-A-Bodies, 7 Dons Drive, Mission, Texas 78572. Phones (956) 581-9959 (Voice), (956) 585-3089 (Fax) E-mail: TABDOLL@aol.com.

These cloth dolls and paper dolls come in a variety of ages and ethnic groups and can be very useful for instruction for some children with deaf-blindness. You would need to be sure that the child can make the association between his or her own body and the doll's body. With adult, child, and infant models, you can teach basic concepts about family.

VIDEOTAPES

Gray, Judi and Jilich, Jitka (1990). Janet's got her period: Training in menstrual self-care for girls and young women with developmental disabilities. Social Biology Resources Centre, Santa Barbara, CA: Distributed by James Stanfield Company, Inc., Phone (800) 421-6534. Web site: http://www.stanfield.com.

This is an excellent video from Australia on menstrual self-care. Even though the actors have accents, the information and repetition used in this video make it an excellent teaching tool to use with some young women with deaf-blindness. The set includes the video material in picture book form, a handbook for parents/teachers, and a set of picture graphics showing the steps in managing menstrual care.

Taylor, Maria Oliva (1991). The GYN exam handbook: An illustrated guide to the gynecologic examination. Santa Barbara, CA: James Stanfield Company, Inc. Phone (800) 421-6534. Web site: http://www.stanfield.com.

This videotape shows a typical gynecological (GYN) exam including a breast and pelvic exam. The set offers videotapes in two formats: continuous version and one divided into sections for ease in starting and stopping. Also included in this set is a still-picture series showing key steps in the examination in a three-ring binder, which can be used to review and discuss each step of the exam. For many young women with deaf-blindness who have some vision, this would be an exceptional aid to preparing them for a GYN exam.

Walker-Hirsch, Leslie, and Champagne, Marklyn P. Circles. Santa Barbara, CA: James Stanfield Company, Inc. Phone: (800) 421-6534. Web site: http://www.stanfield.com.

Circles I: Intimacy and Relationships
Circles II: Stop Abuse
Circles III: AIDS: Safer Ways

These materials include wall graphics, twenty-six videotapes, graph icons, and teacher's guides. The "circles" concepts use color-coded concentric circles on a teaching graphic to teach relationships, personal boundaries, and so forth. The videotapes are lessons on different aspects of sexuality and relationships. This is a very nice curriculum for non-deaf-blind developmentally disabled individuals. Perkins School for the Blind has used this curriculum with extensive adaptation for some deaf-blind students. Although the entire set of three is very expensive, the three units can be purchased separately.